

Studying Cost as a Factor in the Choice between Quality and Quantity of Life amongst Patients with Cancer and their Caregivers at a Cancer Centre in Singapore

Keson Tay¹, Lee Jiayu Rachel¹, Sim Shin Wei Dorsett², Sumytra Menon³, Ravindran Kanesvaran^{4,5}, Rukshini Puvanendran^{5,6} and Lalit Kumar Radha Krishna^{5,7}

¹Yong Loo Lin School of Medicine, National University of Singapore, Singapore

²Singhealth Residency, Singapore

³Lien Centre for Palliative Care, Duke-NUS, Singapore

⁴Division of Medical Oncology, National Cancer Centre Singapore, Singapore

⁵Tutor Practice Course 2, Duke-NUS, Singapore

⁶KK Womens and Children's Hospital, Singapore

⁷Division of Palliative Medicine, National Cancer Centre Singapore, Singapore

*Corresponding author: Lalit Kumar Radha Krishna, Senior Consultant in Palliative Care, National Cancer Centre Singapore, Singapore, Tel: +65 64368000; E-mail: Lalit.krishna@nccs.com.sg

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Abstract

Background: Treatment costs and sociocultural concerns play a significant role in decisions regarding Quantity of Life (QuoL) options that seek to prolong life, such as chemotherapy, or a Quality of Life (QoL) approach where the patient refuses available treatments such as chemotherapy in favour of maximizing comfort and quality of life at the end of life in Singapore. Deciphering the reasons behind such care decisions is often difficult because of local social taboos regarding discussions about death and dying.

Objectives: To scrutinize the rationale behind QuoL and QoL within the Singapore context and delineate the impact of cost upon such decisions.

Methods: To overcome local sociocultural taboos about discussing death and dying with patients, participants watched a video vignette of a family discussing treatment options for their mother (Mrs Tan) who was recently diagnosed with terminal cancer. Participants were asked what advice they would offer Mrs Tan regarding her treatment plans in the face of a poor prognosis, incurable cancer and costly treatment. Participants were then asked what their advice would be when the costs of treatment was covered by the patient's insurance policy. Their responses were evaluated using Grounded Theory analysis.

Setting/Subjects: 132 oncology patients and their caregivers were recruited from an ambulatory treatment unit at a tertiary oncology centre.

Results: 63 (47.7%) of 132 participants advised Mrs Tan to opt for the QoL approach but when treatment costs were covered by insurance, only 5 (3.8%) of 132 participants chose QoL, whilst 108 (81.8%) participants chose QuoL options.

Conclusion: Whilst cost is a significant factor in end of life decision making, strong sociocultural influences that perceive QoL approaches as 'giving up' ultimately determines the course of care.

Keywords: Quality of Life; Palliative medicine; Decision-making; End-of-life care; Treatment costs

Introduction

End of life decision making processes within the Singaporean context do not always prioritize the best interests of the patient [1-18]. Underpinning these concerns are three local practices. First, the continued dominance of family centric decision-making in end of life care, where decisions may favour the family's interests rather than the patient's. Second, local conceptions of Confucian inspired filial piety

which requires that the family provide for the financial, physical, social, spiritual and emotional needs of the patient in recognition for their previous contributions to the family or as a result of their place within the family unit [1-18]. Third, mounting care costs do create potential for conflicts of interests in meeting the duty to care for the patient and the primacy placed on protecting the interests of the family. On one hand financial costs of caring for the patient at the end of life may see families conflicted over the pursuit Quantity of Life (QuoL) options that seek to prolong life such as chemotherapy or a Quality of Life (QoL) approach where available treatments such as

chemotherapy is declined in favor of maximizing comfort and quality of life [19-34]. On the other social expectations to provide continued care of patients see families sometimes opt for sometimes 'futile' treatments in order to meet their filial obligations.

Singapore's Health Care System

Singapore's healthcare financing structure combines government subsidies with compulsory individual medical savings accounts called Medisave, which all working Singaporeans and their employers pay into monthly [20]. This "compulsory individual medical savings account scheme, which allows practically all Singaporeans to pay for their share of medical treatment" may be supplemented by Medishield insurance, the government's basic healthcare insurance plan [19-21]. More comprehensive cover may be purchased through an integrated Medishield insurance plan [21]. All these schemes are subject to withdrawal limits and co-payments. Despite generous government subsidies, patients and their families may have to bear some out-of-pocket expenses [2,19-25]. Such expenses may include costs of renting medical equipment for home care and fees for some professional caregivers [22,23]. When the patient's Medisave account is depleted, the family member's finances may be affected as they dip into their own Medisave accounts or own savings to make payment instead [22,23].

Although it may be argued that family members are not obliged to do so, they often do in the face of regnant sociocultural beliefs that emphasize familial obligations to care for ill family members [1-18].

Filial Piety in Singapore

Filial piety revolves around the expectation that adult children must care and support their elders in recognition of the care they received earlier [31,35,36]. This obligation is often met in two ways, the provision of emotional, spiritual, physical and financial support at the end of life and by maintaining the patient's 'hopes' and reducing 'stress'. The former often translates to doing everything possible to prolong the life of the patient. The latter is seen as critical given that a loss of 'hope' or the presence of stress during periods of illness especially at the end of life is believed to hasten death. The culmination of both these factors often sees children colluding with health professionals to hide or moderate the diagnosis and/or prognosis to protect the parent from 'concern and anxiety', over their life-limiting illness and not infrequently pursuing second 'opinions', alternative treatment options and even futile treatment options in order to prolong the life of the patient [3-6,28-49].

The wider family and community police compliance of filial obligations [29,31-44]. Failure to meet these societal and familial standards is said to result in a 'loss of face' or personal honour for the immediate family, a fate fearfully avoided within the local community [4,14,29,31,33]. Thus being seen to be filial and to be meeting one's duty to care for the patient is critical to some.

Views of Quality of Life Advocates

Given the societal backdrop, advocates for a Quality of Life (QoL) approach to care are often regarded suspiciously by families and by the wider society and this has an impact on end of life decision-making. Elucidating the views of patients and their caregivers as to QoL and QuoL options has a significant impact upon how end of life care and palliative and hospice care is perceived locally.

Study Methodology

Subjects

All patients and their caregivers were recruited from the Ambulatory Treatment Unit at the National Cancer Centre Singapore. Written informed consent was obtained from participants prior their participation in this Singhealth Centralized Institutional Review Board approved study. A total of 136 patients and caregivers were interviewed. Four interviews were incomplete and were excluded from data analysis given that they did not proceed beyond collection of demographic data (Table 1).

Number of participants	132
Male, n (%)	48 (36.4)
Female, n (%)	84 (63.6)
Age, Mean (SD)	49.7 (12.5)
Race, n (%)	
Chinese	109 (82.6)
Malay	3 (2.3)
Indian	15 (11.4)
Other	5 (3.8)
Education level, n (%)	
No formal education	2 (1.5)
Primary	24 (18.2)
Secondary	60 (45.5)
Tertiary	38 (28.8)
Professional qualifications	8 (6.1)
Marital status, n (%)	
Single	14 (10.6)
Married	110 (83.3)
Divorced	3 (2.3)
Widowed	5 (3.8)
Housing, n (%)	
2/3-Room flat	18 (13.6)
4-Room flat	82 (62.1)
Private condominium	13 (9.8)
Landed property	15 (11.4)
Other	4 (3.0)

Table 1: Respondent Demographics.

Participants and eligibility criteria

Convenience sampling was used to recruit patients, aged 21 or older, with a cancer diagnosis (any stage), and able to understand

English or Mandarin. Patients identified primary caregivers, whom we recruited. They also had to be at least 21 and able to understand English or Mandarin. Nine trained interviewers carried out all the audio-recorded interviews. Transcription and translation to English (when required) was carried out by two of the authors.

Methodology

In deference to cultural sensitivities on discussing end of life issues, and in order to produce a less threatening means to explore sensitive topics, a video vignette was shown separately to patients and caregivers [4,14]. The video scenario depicted a family of three adult children who were discussing the treatment options for their mother (Mrs Tan) who was diagnosed with an advanced and incurable cancer. The doctor estimated that Mrs Tan would survive for seven to ten months if she opted for chemotherapy, or four months if she did not. Each adult child expressed a different view of how to proceed. One daughter focused upon the prohibitive costs of potential treatment compounded by the families' financial difficulties following aggressive and expensive cancer treatment for their father who passed away last year. The second daughter focused upon the maximisation of Mrs Tan's quality of life (QoL) in the face of treatment side effects and poor anticipated response to chemotherapy. (This approach does not negate treating remediable causes of deterioration). Mrs Tan's only son advocated a quantity of life (QuoL) approach which focuses on life prolonging efforts. We asked participants a series of questions using a semi-structured questionnaire to scrutinize the impact of cost on treatment decisions. This questionnaire was designed using prevailing local data, feedback from patients, and input from our panel of local experts.

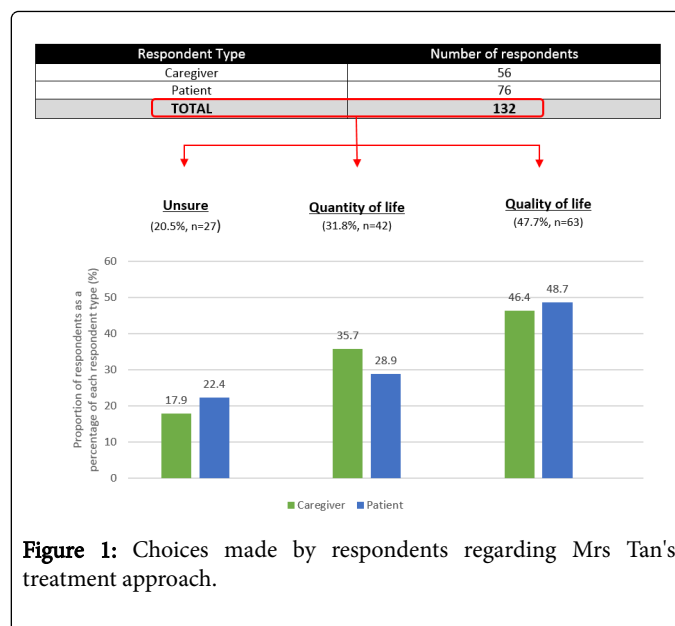
Coding

The completed transcripts of the audio-taped interviews were labelled with unique numeric identifiers and de-identified. The 132 completed transcripts were coded manually and independently by three members of the investigating team. We used Grounded Theory to identify key ideas, which evolved during thematic analysis. Saturation of thematic analysis was attained within the first 30 cases and there were no contradicting data in the following 100 cases. Any discordance in the coding was discussed by all the members of the team and a majority verdict was applied. Not all questions were answered by the participants and caregivers. This was mainly because they were called away for treatment.

Results

The choice between quality and quantity of life

Participants were asked whether Mrs Tan should pursue a quality of life (QoL) approach to avoid any side effects and conserve the family's financial resources, or adopt a Quantity of Life (QuoL) approach, which involved treatment such as chemotherapy but would likely cause side effects and be expensive. Of the 132 responses, 47.7% (63) opted for a QoL approach, 31.8% (41) preferred a QuoL approach and 20.5% (27) were unsure (Figure 1).



Caregivers

Twenty (35.7%) of 56 caregivers opted for QuoL measures (Figure 1). Caregivers believed this approach was optimistic, avoided 'bad' news, maintained hope and supported the patient. Most were "not yet ready to let go" and wished for the patient to keep fighting.

Twenty six (46.4%) of the 56 caregivers preferred QoL and although QoL was important, it "was not worth it" if the patient suffered as a result. Ten (17.9%) caregivers struggled to determine what was best for the patient.

Patients

Thirty seven (48.7%) of the 76 patients valued QoL over QuoL, citing concerns about the side effects of chemotherapy, Mrs Tan's age at diagnosis and poor prognosis. Most (91.9%) of these 37 patients saw the cessation of treatment as the natural end-point to Mrs Tan's disease journey.

Twelve (32.4%) of these 37 patients saw a QoL approach as something to "settle for" if there were no treatment options, treatment was unaffordable or treatment side-effects were unbearable.

Conversely 39 (51.3%) patients chose QuoL because it offered a 'chance' to prolong life, ameliorate suffering and demonstrated the patient did not give up. Seventeen (22.4%) of 76 patients were unsure given insufficient information featured in our vignette.

Time

The most significant consideration in the choice between a QoL and a QuoL approach was how best to use the time remaining. Of the 71 respondents, 36 (50.7%) favoured a QuoL approach, while 35 (49.3%) favoured QoL. Patients (31.6%) veered toward QoL measures and caregivers (33.9%) preferred QuoL measures (Figure 2).

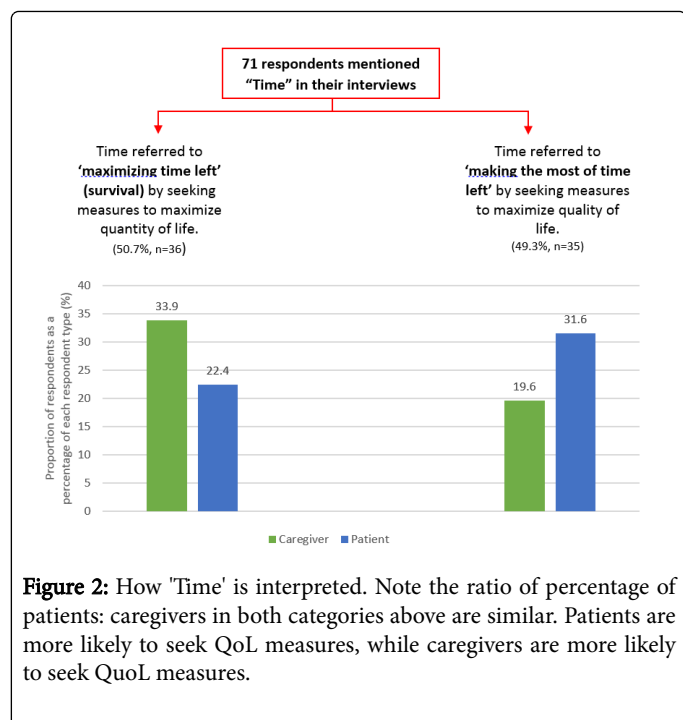


Figure 2: How 'Time' is interpreted. Note the ratio of percentage of patients: caregivers in both categories above are similar. Patients are more likely to seek QoL measures, while caregivers are more likely to seek QuoL measures.

Importance of cost

More than 80% of our participants indicated that their treatment decisions were dictated by treatment costs (Figure 3).

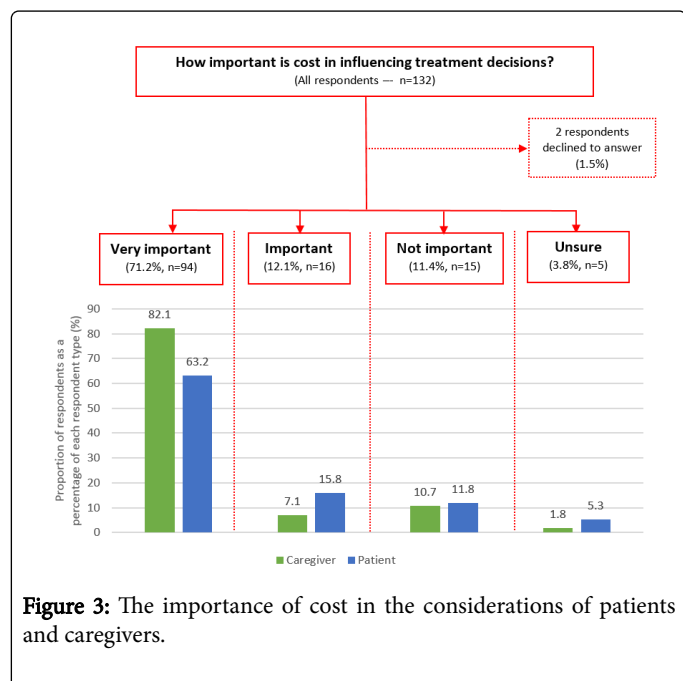


Figure 3: The importance of cost in the considerations of patients and caregivers.

Sixty (78.9%) patients and 50 (89.3%) caregivers said cost was very important or important whilst 9 (11.8%) patients and 6 (10.7%) caregivers reported that cost were unimportant. The remainder were unsure.

When the importance of cost is negated

When costs were covered by insurance and care effectively 'free', 109 (82.6%) of 132 participants said they would opt for a QoL approach. Five participants (3.8%) maintained a QoL approach and 18 (13.6%) were unsure. The rationale for a QoL approach even at the cost of QoL revolved around hope and maximising their chances of survival and even cure. "Just try it out" and "Why not go for it?" conveyed the dominant sentiments even amongst those who had previously chosen QoL over QuoL (Figure 4).

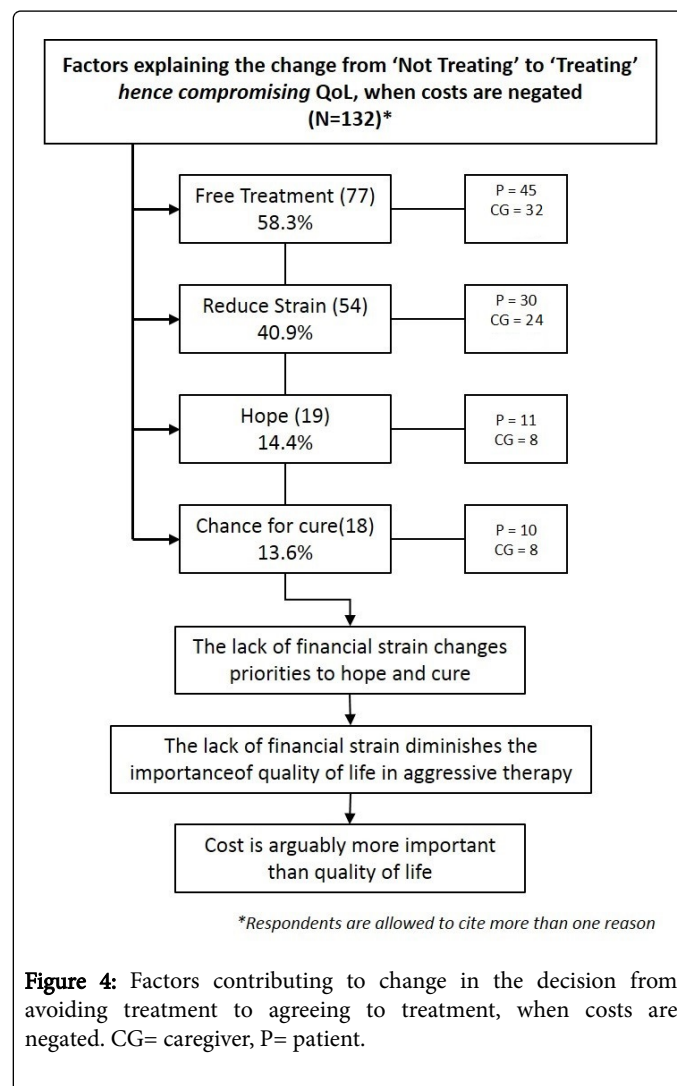


Figure 4: Factors contributing to change in the decision from avoiding treatment to agreeing to treatment, when costs are negated. CG= caregiver, P= patient.

When cost was irrelevant, respondents heavily favoured QoL (Figure 5). The proportion of patients choosing QoL shifted from 28.9% (22 of 76 patients) to 82.9% (63 of 76 patients), and the proportion of caregivers choosing QoL shifted from 35.7% (20 of 56 caregivers) to 80.4% (45 of 56 caregivers).

Two (3.6%) caregivers maintained their QoL position despite free treatment based on 'social concerns' such as the need to accompany patients to therapy, changes in lifestyle, and the potential for "suffering". Forty-five (80.4%) caregivers stated if treatment was free the risk-benefit analysis tipped in favour of a QoL approach.

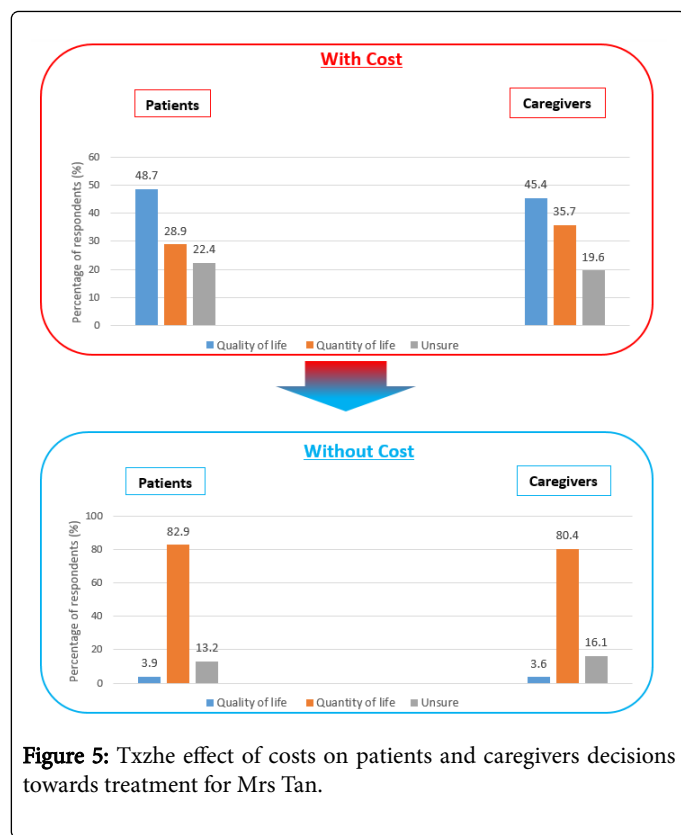


Figure 5: The effect of costs on patients and caregivers' decisions towards treatment for Mrs Tan.

Discussion

Our data suggests that decisions between QoL and QuoL options in terminal cancer are defined by cost concerns. But the truth is more nuanced. A review of participant responses revealed that there was a poor understanding of QoL measures and palliative care, which was equated to 'giving up' and abandonment. So, it is unsurprising that most participants believed that a QoL approach is only acceptable when care costs are prohibitive, and when there was little realistic chance of improving the patient's condition. Patients and caregivers believed free treatment cannot be rejected when the patient looked as "well" as Mrs Tan was. Patients are also expected to set an example by 'fighting on' and not 'giving up' rather than adopting a QoL approach perceived as 'wishing to hasten death'. Failure to meet these expectations reflects poorly on the family and is liable to result in a loss of 'face'.

Caregivers felt obliged to opt for the QuoL approach when treatment was free because it was "easier to live with" and relieved their concerns of guilt and abandonment. Whilst they are expected to protect familial interests, they are also expected to continue to provide physical, financial, emotional and spiritual care, maintain hope and not abandon family members [31,49]. Many caregivers reported being ill-prepared for either the pressures of being decision-makers or the inevitable scrutiny of their intentions should they opt for a QoL approach when treatment is free.

Study Limitations

The primary limitation of our study is the variances in the pervasiveness and the interpretation of filial obligations amongst

participants. However consistent with prevailing data our findings do highlight the continued albeit evolving role filial obligations have upon the manner that end of life decisions are made in Singapore [31, 45-49].

Conclusion

This study into the considerations behind end of life decision making in Singapore indicates that cost is a significant factor in treatment decisions. However, filial obligations and societal expectations also have an impact and should not be underestimated. Excessive cost and poor prognosis are more palatable reasons not to pursue treatment rather than stating the interests of the family outweigh those of the patient. Whilst efforts to make treatment options more affordable continue to be welcomed, demystifying the role and purpose of a QoL approach will promote patient centered and allow palliative care to thrive.

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