

Research Article

Perceptions of Quality-of-life Advocates in a Southeast Asian Society

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ABSTRACT

In family-centric societies, maintenance of hope amongst ill family members is a pivotal duty of the family. Meeting this duty often takes the form of continuing treatment even when such options may be futile. This makes efforts to maximize quality-of-life options challenging. We explore Singaporean perceptions surrounding quality-of-life advocates who advice quality-of-life measures over potentially life-prolonging treatment in terminal illness using a novel video vignette based

semi-structured interviews. Findings suggest that quality-of-life advocates are viewed as failing in their filial obligations and perceived as 'selfish', 'money-minded' and 'immoral'. These findings highlight the need to educate patients and caregivers about quality-of-life approaches.

Keywords: Quality of life; End-of-life; Palliative care; Decision-making; Asia

Introduction

The influence of culture upon end-of-life decision-making is well-established [1]. In Singapore, Confucian-inspired beliefs see the family being responsible for the care of ill family members [2-6]. The expectations to care for family members is manifest in two pivotal ways. One, obligations to provide care and sustenance take two forms. First, provision of effective care encapsulates the maintenance of hope [7]. This is interpreted as 'protecting' the patient from 'bad news' which would likely precipitate a loss of hope, lead to depression, 'giving up' and hastening of death [7]. Second, protecting a patient from 'bad news' which may be variously interpreted by the patient leads families to circumnavigate direct patient involvement in care determinations and pursue familial-led determinations of care [2]. Underpinning this practice is the duty of non-abandonment [7].

Two, under the aegis of the duty of non-abandonment, the family must seek to prolong the patient's life [2]. As a result, some families pursue sometimes futile, unproven and even burdensome treatment options [2]. A failure to do so is seen by some Singaporeans as a failure of the family's filial obligations [2,8-11]. For family members, failure to meet filial obligations predisposes the threat of a loss of 'face', which within the local context translates to a loss of personal honour and dignity - a fate fearfully avoided within this family-centric society [2].

Considering prevailing culture, it is unsurprising that decisions not to pursue Quality of life (QoL) options at the cost of available disease altering and potentially life prolonging options are rarely supported by family or society [8,9,12-15]. Yet, evolving clinical situations and increasing treatment costs as patients live longer with the burden of cancer and the side effects of cancer treatment appear to suggest changes in the manner that these cultural and societal beliefs, mores and values are interpreted [15,10,16]. Understanding how society perceives

decisions for QoL and QoL advocates (family members that advocate QoL options when disease altering and potential life prolonging options remain) will help local education initiatives to increase awareness of patient choice and end-of-life decision-making [8,9,14,17].

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Methods

Study design

Design of this study was largely determined by social and cultural considerations [18-20]. To overcome local sensitivities with regards to discussing death and dying [7], we employed the use of video vignette and individual face-to-face semi-structured interviews with patients, their caregivers and/or their decision-makers [18-20]. This is the first time that we are aware of that this approach has been adopted [18-20]. Previous studies on death and dying in Singapore were limited to short interviews and there have been no studies that we are aware of that have studied the issue of QoL or QoL advocates in Confucian inspired family-centric communities [8,9,18-21]. The video vignette served to distance and depersonalizes discussions about death and dying which was critical given the study populations. The video vignettes provided an avenue to introduce the topic of a QoL approach, the positions taken by QoL advocates and to differentiate QoL approaches from palliative approaches where no life-prolonging treatments exist.

The 15 min video revolved around the advice and actions of three children in proposing different treatment approaches for their 70 year old mother, Mrs. Tan, who had just been diagnosed with Stage IV colon cancer. In the video, it was also disclosed that Mrs. Tan's spouse had succumbed to cancer a year ago following an expensive, protracted and ultimately futile course of chemotherapy. Each character within the video was modelled on a composite of patient narratives, paying careful attention to ensure identifiable characteristics were changed (Table 1).

Mrs. Tan's son, Shen, proposed a quantity of life (QuoL) approach. Shen is depicted as a fiercely filial son, who, despite being aware of Mrs. Tan's limited prognosis, poor likelihood of clinical response to chemotherapy and the family's financial constraints, advocates for life-prolonging treatment.

Shiao, Mrs. Tan's daughter, advocated a QoL approach based upon her mother's poor prognosis and the likely impact

of chemotherapy upon Mrs. Tan's physical condition. Shiao also highlighted the family's poor financial situation and the impending strain upon the family with her own impending nuptials, the birth of her brother's second child and her sister's plans to move to Shanghai.

Wen, Mrs. Tan's other daughter, also advocated a QoL approach, based upon her assessment of her mother's psychological state. Wen explains that her mother was still recovering from Mr. Tan's death and was not psychologically prepared for such treatment. Wen also argued that Mrs. Tan would not wish to have similar treatment given her experiences caring for Mr. Tan as he underwent chemotherapy with very little meaningful prolongation in his life expectancy.

The video and the semi-structured questionnaire was designed by a panel of local experts and drew upon prevailing local data, feedback from patients, relevant theories, refined key issues that required addressing, psychological factors, participant's characteristics and cultural and religious factors [18-20].

The interviews contained four sections. The first addressed conceptions of collusion and discussions about the duty of the family to protect the patient for 'bad' news. The second revolved around prevailing concepts of QoL and how QoL advocates were viewed. The third addresses how filial piety is conceived and the extent of care that is expected in respecting the Duty of Non-abandonment and Duty of Care contained within the concept of filial piety. The fourth stage addresses the duty of the family to fund care and the various factors considered in determinations to fund a patient's care. Here we present data from the second part of the interview. Our face-to-face semi-structured interviews with patients, their caregivers and/or their decision-makers, asked participants about what advice they would give Mrs. Tan, the rationale for this advice, their views of Mrs. Tan's children who gave similar advice and what underpinned these perceptions. The instructions to participants, fact sheet and the completed video vignette were reviewed by a panel of local experts to ensure that it was balanced, reflected the realities of local experience and was sensitive to cultural and social beliefs.

Participants

Participants were patients and their caregivers and/or their decision-makers attending the Ambulatory Treatment Unit (ATU) in the National Cancer Centre Singapore between April 2014 and June 2014. A caregiver was defined to be a family member identified by the patient to be their primary care provider. The decision-maker was the person identified by the patient to make care determinations for them. The decision-maker need not be the primary care provider.

Eligibility criteria

Convenience sampling was used to recruit patients, their caregivers and or decision-makers as they attended the ATU for the patient's chemotherapy. Written informed consent was obtained from participants in this Sing Health Centralized Institutional Review Board approved study. The recruitment criteria employed is summarised in (Figure 1).

Table 1: Character, description and opinions held by each character.

Characters	Opinions
Son	Quantity of life above all else
Daughter with short hair	Quality of life because of its effect on mother's physical and mental well-being
Daughter with long hair	Quality of life after weighing up prognosis and cost

Footnotes: Opinions of the characters in the video

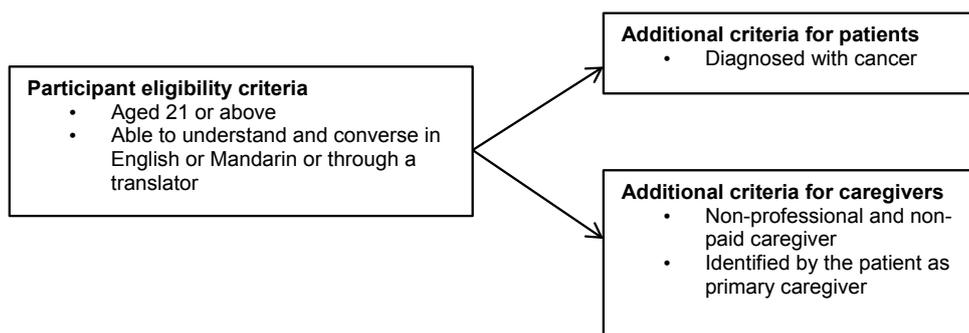


Figure 1: Recruitment criteria.

Interviews

Interviews lasted between 20-45 min. Each interview was audio-recorded, transcribed verbatim, de-identified and labelled with unique numeric identifiers. Three senior investigators coded all the transcribed files independently to reduce bias.

An iterative review saw participants asked additional questions regarding their own advice for Madam Tan and how they would view the children that advocated different positions.

In the absence of an a priori framework and a lack of understanding of decision-making processes in Singapore, we adopted [22,23]. Constructivist concept of the Grounded Theory [24-26]. Constructivist concept of the Grounded Theory facilitates understanding of ‘what influences the perceptions of participants’ derived “through the development of theoretical explanations that are ‘grounded’ in practical experiences” Lingard et al. and Creswell, Charmaz’s concept considers the influences of our clinical experiences, background and belief in coding and interpreting this data [22,23,25,26].

The Grounded Theory allows for common themes from various accounts to be categorized, whilst the iterative process allowed “whatever is theoretically relevant to emerge” and drive future data collection (theoretical sampling) [27-29].

Results

A total of 139 semi-structured interviews were conducted. Thematic saturation of this second part of the interviews were attained after 37 interviews and no contradictory data was identified from the remaining interviews. 132 interviews were completed, seven were abbreviated due to treatment commencement (of these seven, three participants did not get beyond collection of demographic details). Of the 132 completed interviews, 11 respondents - five patients and six caregivers - declined to answer some of the questions. Two recordings had insurmountable technical problems towards the end of the interviews. Of the 119 fully-completed questionnaires, 66 were by patients, 53 by caregivers. Forty-eight of the 53 caregivers were women who were either the patient’s spouse or daughter. There were 11 unaccompanied patients, 4 triads that consisted of two caregivers and a patient and 48 dyads of patients and caregivers.

All participants were asked whether they would advise Mrs. Tan to pursue life-prolonging measures or QoL, the rationale for this advice, their view of the children that advocated the same view and the rationale for their perception of a child

who proposed similar treatment as they did. For example, if a participant had suggested use of QoL measures, they were asked how they viewed Shiao who advocated QoL measures based on Mrs. Tan’s prognosis and for financial reasons or Wen, who advocated QoL measures based upon Madam Tan’s physical and well-being. They were then asked why they held either a positive or negative view of the children that provided similar advice and of the remaining children.

Table 2 describes the demographics of 130 respondents

Table 2: Respondent demographics.

Number of participants	130
Male, <i>n</i> (%)	48 (36.9)
Female, <i>n</i> (%)	82 (63.1)
Age, Mean (SD)	49.7 (12.5)
Race, <i>n</i> (%)	
Chinese	107 (82.3)
Malay	3 (2.3)
Indian	15 (11.5)
Other	5 (3.8)
Education level, <i>n</i> (%)	
No formal education	2 (1.5)
Primary	24 (18.5)
Secondary	60 (46.2)
Tertiary	36 (27.7)
Professional qualifications	8 (6.2)
Marital Status, <i>n</i> (%)	
Single	14 (10.8)
Married	110 (84.6)
Divorced	3 (2.3)
Widowed	3 (2.3)
Housing, <i>n</i> (%)	
2/3-Room flat	18 (13.8)
4-Room flat	82 (63.1)
Private condominium	13 (10.0)
Landed property	14 (10.8)
Other	3 (2.3)
Religion, <i>n</i> (%)	
Christianity	37 (28.4)
Buddhism/ Taoism	55 (42.3)
Islam	5 (3.8)
Hinduism	10 (7.7)
No religion/ Free thinker	23 (17.7)

(including the two whose interviews were abbreviated). Patient and caregiver data will be presented separately.

Following a review of all 132 transcripts, the three authors independently began to identify 'detail rich' codes from each transcript [29,30]. Transcripts were reviewed several times as the codes were studied and as a 'code book' of definitions and the 'surface' meaning of the data was created. Codes were constructed from the 'detail rich', 'surface' meaning of the data "across an entire data set" [29]. Semantic themes were identified by grouping the codes. The data was regularly reviewed to ensure all relevant excerpts for each theme were collated and collapsing themes where appropriate to ensure consistency [29].

The themes proposed and defined by each reviewer were compared and discussed online and then face-to-face at reviewers' meetings to review. A review of the full text articles was carried out and "negotiated consensual validation" adopted when coding conflicts and/or disagreement on the themes proposed were identified. In all cases consensus was achieved between all the authors.

a) Patients views

Sixty-six patients completed this part of the study. Eighteen suggested that Mrs. Tan pursue a QoL approach and 33 participants advocated life-prolonging measures. Fifteen respondents reported that they did not know ('Don't know') what to advise. The participant's perspectives of the children who advocated similar positions were stratified into positive (+ve) or negative (-ve) view (Figure 2).

i) Quality-of-life perspective

Forty quotes were provided by the 18 patients who proposed a QoL approach for Mrs. Tan. Two respondents advocated for a QoL approach as they were concerned about Mrs. Tan being a burden to the family, 13 were concerned about the threat of suffering, five were concerned about Mrs. Tan's advanced age and 12 participants based their advice on their understanding of her prognosis. Two of 18 QoL advocates had a positive view of Shiao and one of Wen, who had both advocated QoL positions. Thirteen of 15 remaining QoL advocates had a negative perception of Wen and two had negative perspectives of both

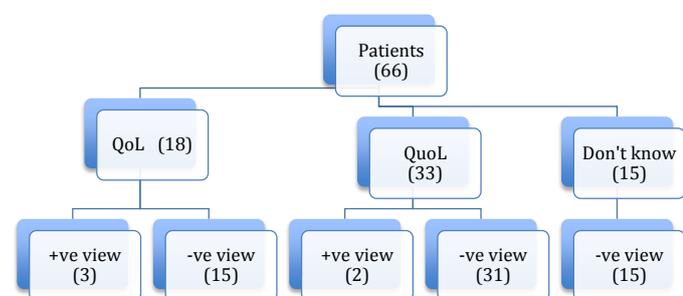


Figure 2: Patients responses. This figure delineates the care approach patients think Madam Tan, (the video character recently diagnosed with stage 4 cancer), ought to adopt. QoL is Quality of Life, QuoL is Quantity of Life. The figure also describes how the QoL advocate (daughter with the short hair named Wen) is perceived. +ve view is a positive view and -ve view is a negative view towards Wen.

Wen and Shiao. These negative perceptions were based upon observations of the interactions in the video and the participant's own life experiences. These included:

1. Wen was selfish and calculative

"So, normally for women, they will be more calculative, counting the money... normally will be like that, quality of life." - Patient 28

2. Wen and Shiao's preference for a QoL approach was due to their 'faulty' attitude and moral beliefs

"I think a caring child will obviously want the mother to go through the thing" - Patient 73

Only one patient thought Wen was advocating a QoL approach because she was concerned with her mother's quality of life.

"She's right that her point of view. So by prolonging its actually we make her suffer before she go off." - Patient 24.

ii) Life prolonging measures

There were sixty-eight quotes from the 33 participants who proposed life-prolonging measures for Mrs. Tan. Forty-eight quotes related to filial obligations to care, maintain hope and non-abandonment.

Two of the 33 patients who suggested life-prolonging measures for Mrs. Tan despite stating that "Treatment is painful." - Patient 67. However both participants advocated life-prolonging measures because they thought it was best for the patient. Both participants held positive views of Wen and Shiao.

Five of the 31 participants who suggested life-prolonging measures believed that Wen and Shiao were motivated by:

1. Poor moral values

"It depends on their moral values, whether their mother is more important than money" - Patient 110

Twenty-four participants who suggested life-prolonging measures believed that Wen

2. Failed in her filial obligations

"Those filial ones will. Those who don't about care her, I don't know lah." - Patient 127

3. Failed in her social obligations

"If she doesn't, then she isn't her daughter anymore" - Patient 105

4. Was uncaring

"The child seems to be saying that she doesn't want her mother to live longer." - Patient 64

Participants believed that Wen was 'callous' and uncaring and thus 'insincere'.

Two participants believed that Shiao's position was flawed.

"If she thinks money is more important, then something is wrong with this person's mind-set and her knowledge." -

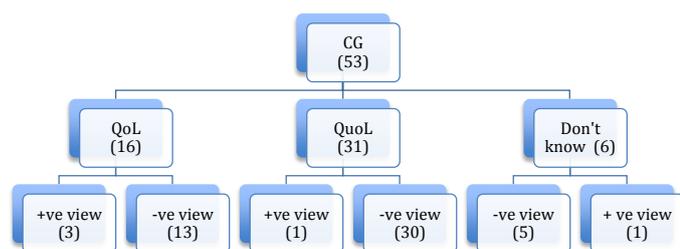


Figure 3: Caregivers responses. The figure delineates the care approach caregivers think Madam Tan, (the video character recently diagnosed with stage 4 cancer), ought to adopt. QoL is Quality of Life, QuoL is Quantity of Life. The figure also describes how the QoL advocate (daughter with the short hair named Wen) is perceived. +ve view is a positive view and -ve view is a negative view towards Wen.

Caregiver 136

b) Caregivers views

Of the 53 caregivers who participated, 16 advised a QoL approach, 31 proposed life-prolonging measures and six were not sure. Three participants who advocated a QoL approach, one who suggested life-prolonging measures and one who was undecided had positive views of Wen and Shiao (Figure 3).

i) Quality-of-life perspective

Of the 37 explanations from the 16 participants advocating QoL measures, 13 pertained to prognosis, 11 on potential suffering, seven on being a burden to the family and six rested on age. Twelve QoL advocates had negative views of Wen and one of both Wen and Shiao.

The views directed at Wen focused on

1. Failing to maintain hope

"It's like the Chinese saying, wait till see the coffin then cry."

Caregiver 139

The negative views of Shiao and Wen revolved around

2. Holding wrong values

"Hoping they value their family. Their love is more important than money." - Caregiver 130

All three QoL advocates who held favourable views of Wen and Shiao focused upon respecting Mrs. Tan choices.

ii) Life prolonging measures

Thirty of the 31 caregivers advocating for life-prolonging measures voiced negative views of the QoL advocates. The views directed at both Shiao and Wen pertained to 'wrong thinking', whilst negative views of Wen were related to failing in her filial obligations.

Discussion

Overall Wen and Shiao were seen to have failed in their filial obligations. The concept of 'wrong thinking' appears to stem from sole reliance upon the prognosis and potential benefits of treatment provided by the doctor. Participants believed

that failure to consider the impact of alternative, adjuvant and supportive treatment options and the benefit of a trial of treatment to see how Mrs. Tan coped were unacceptable. Individual determinations of QoL were also seen to be biased and difficult to substantiate.

Decisions to respect Mrs. Tan's wishes too were wrong even though she had calmly stated the reasons for her refusal of chemotherapy. Participants believed that discussing QoL measures negatively influenced the patient's position. Some participants believed that Mrs. Tan was in shock from the diagnosis and had opted for QoL measures because of this. Some participants believed that Mrs. Tan's thinking was affected, as she was depressed and still grieving.

Participants believed that Mrs. Tan's was 'testing the waters' to assess whether they would support her treatment. Mrs. Tan was doing so to not appear demanding or placing her own interests over those of the family. Wen and Shiao's failure to 'correct' Mrs. Tan's position was a significant 'failing' as was failing to show more concern for her immediate emotional needs. Participants believed that delaying treatment decisions till Mrs. Tan and the family had had time to consider all the options might have been a better option. Sincerity in meeting filial obligations is pivotal. Wen was perceived to be insincere and motivated by self-interests rather than a genuine concern for her mother's psychological and physical wellbeing for five reasons.

First, participants determined that Wen was insincere based on their own experiences rather than the manner that Wen was portrayed in the video, suggesting their ability to relate to the video vignette. Second, participants believed that adopting a QoL approach was 'wrong thinking' as it placed self-interests over those of her mother as Wen had clearly not supported her mother sufficiently. Third, participants believed that Wen's position was speculative and ultimately aimed at justifying her concerns about the economic costs of the treatment rather than the emotional and physical costs upon her mother's wellbeing. Participants concluded this as Wen had not admonished Shiao as Shen had done when she had talked about financial reasons not to pursue treatment. Fourth, Wen was insincere as she failed to support her mother's emotional needs after she was told the diagnosis. Participants drew these conclusions from their own beliefs and experiences rather than solely from the video. Fifth, respondents believed that Wen had been insincere as she failed to advocate for a trial of treatment to gauge treatment response and treatment side effects. The QoL advocate who has not holistically assessed a situation and or seen to have employed speculative means to validate refusal of life-prolonging treatment is considered with suspicion. This may explain why Shiao, who also advocated for a QoL approach, was spared negative comments. Participants appeared to accept Shiao's assessment as it was based upon the verifiable reasons of the financial toxicity of chemotherapy treatment upon the family and the limited anticipated benefits that Mrs. Tan was likely to glean from chemotherapy. Further, Shiao's position is validated by another Confucian belief, which confers primacy of familial interests over the interests of the individual [3]. This justifies

relegating filial obligations and prioritizing the interests of the family. Our data does suggest that 'unquestioning' compliance with filial obligations without due consideration of wider ramifications is not an indicator of fealty. Rather what is critical to the acceptability of a decision for QoL is the sincerity of the action.

Limitations

There are several limitations within our study. The gender of the three children and the positions they took may have introduced gender bias and cannot be ruled out despite advice from local experts and feedback patient representatives who suggested that these gender biases may be overstated. This is evident in Patient 28's statement "So, normally for women, they will be more calculative, counting the money...normally will be like that, quality of life."

Cultural and ethnic stereotypes too cannot be ruled out despite the inclusion of participants from a wide spectrum of ethnic, religious, social and cultural backgrounds. Similarly, bias arising from the responses of participants must be considered given that these were patients and caregivers who had opted to pursue life prolonging measures and disease modifying treatment options even though most patients had early stages of cancer. The impact of responses of patients and caregivers who had declined treatment, were in the latter stages of their illness and/or had chosen for QoL options ought to be considered

Future Research

A significant limitation of this study was its design. Exclusion of non-English speaking participants limited the participation of different cultural and economic groups. Use of oncology patients and their families having treatment created further bias. It would have been useful to assess how QoL advocates are viewed when treatment costs are mitigated.

In addition, a significant concern in this study was that many participants arrived at their position with respect to QoL advocates from their own experiences rather than from their observations of the interactions of the various children in the video. These considerations suggest the need for a dedicated study of perceptions of QoL advocates amongst oncology and palliative care patients and their families as well as the public.

Conclusion

These findings suggest that the largely historical, ethical and philosophical-based interpretations of Confucian concepts have given way to a more holistic clinically-relevant and culturally-sensitive model. Compliance with filial obligations no longer trumps the personal autonomy of family members.

The implications of these findings are stark for several reasons. One, to remain relevant to daily life Confucian concepts has continued to evolve in line with its pragmatist roots. As a result, assumptions surrounding local concepts of end of life decision making processes require careful and holistic reconsideration on an individualized level [31-35].

Two, it is critical that the views of the patient are adequately explored and that patients are told of the impact of the treatment choices available [8,9,11-13]. Such review must be carried out subtly and with sensitivity particularly given local sensitivity with regards to death and dying [8,9,11-13].

Three, the data highlights the need for effective timely and sensitive facilitation of family discussions WITHIN the family particularly when life prolonging measures are neither the patient's choice nor in their overall best interests. To facilitate such roles healthcare professionals need to be trained in specific communication and facilitating skills to introduce and support end of life discussions where QoL approaches can be framed as 'meaningful', 'of value' and as a viable alternative to life prolonging measures.

Four the impact of decision-making in end of life needs to account for the manner that QoL advocates are seen and the need to protect the interests of caregivers particularly when their advice risks censure, a loss of 'face' and potentially rifts with the rest of the family [8,9,11-13]. More context specific culturally sensitive qualitative study is required as are studies upon the impact of referrals to Palliative Care.

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