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Development of Preference Weights for the 10-item Singapore Caregiver Quality Of Life Scale: A Discrete Choice Experiment

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Development of Preference Weights

for the 10-item Singapore Caregiver Quality Of Life Scale:

A Discrete Choice Experiment

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Abstract

Background

Evaluating informal caregivers' quality of life (QoL) is essential for health economic evaluations. However, commonly used preference-based, caregiver-specific instruments lack anchoring to death, hindering the calculation of quality-adjusted life years. Furthermore, these instruments were developed in Western countries, leaving a gap for culturally appropriate instruments originally established in the East. This study aims to develop preference weights for the validated 10-item Singapore Caregiver Quality Of Life Scale (SCQOLS) to establish a culturally appropriate, death-anchored utility framework.

Methods

An online survey was administered to caregivers residing in Singapore and caring for adults. The questionnaire comprised discrete choice experiment (DCE) and visual analogue scale (VAS) tasks. DCE data were fitted to a conditional logit model. The DCE latent utility was anchored to death by mapping the VAS data onto the dead-full health scale, generating the SCQOLS preference weights for utility computation. Respondents' SCQOLS utility was compared with the EQ-5D-5L utility for discriminative ability. Concurrent validity and test-retest reliability were evaluated using external data.

Results

Among 1,036 respondents, 925 who passed data quality checks were analyzed. They had a mean age of 38.6 years, 51.8% were female, 24.5% were sole informal caregivers, and 68.6% cared for their parents. The items "*Poor appetite*" and "*Uncertain financial situation*" were the most important (relative importance 15.3% and 14.5%, respectively), whereas "*Aches and pains*" was the least (6.2%). The SCQOLS utility ranges between 0.247 and 1. The sample mean was 0.730 (standard deviation: 0.131), with no floor effect and a mild ceiling effect of 1.51%. It demonstrated non-inferior discriminative ability to the EQ-5D-5L utility, and exhibited strong concurrent validity against the Brief Assessment Scale for Caregivers (correlation coefficient ≥ 0.714) and satisfactory test-retest reliability (intraclass correlation ≥ 0.821).

Conclusions

The SCQOLS preference weights will facilitate health economic evaluations, supporting healthcare decision-making and resource allocation in Singapore, with potential extension to other Asian countries.

Keywords

- Caregiver, Health economic evaluations, Preference-based instrument, Preference weights, SCQOLS, Utility.

Introduction

Thanks to economic growth and technological advancement, the life expectancy of the world population is longer than ever before [1]. However, this longevity has unfortunately been accompanied by an increased burden of debilitating illness, which has driven an escalating demand for informal caregivers [2]. Recently, the importance of evaluating informal caregivers' quality of life (QoL) has been emphasized by healthcare authorities [3,4]. These recommendations highlight the use of preference-based instruments to assess informal caregivers' QoL, enabling computation of health utilities for integration into health economic evaluations.

Nevertheless, commonly used preference-based instruments for assessing caregivers' QoL, such as the Adult Social Care Outcomes Toolkit for Carers (ASCOT-Carer), Carer Experience Scale (CES) and CarerQol-7D, are not anchored to death [5-8]. Consequently, utility values scaled on the conventional dead-full health (0-1) metric, and in turn quality-adjusted life years (QALYs), cannot be computed [9,10]. Moreover, while these instruments were all developed in Western countries, there remains a lack of preference-based instruments established in the East which is culturally more appropriate for Asian caregivers.

The Singapore Caregiver Quality Of Life Scale (SCQOLS) is a 51-item, profile-based instrument developed and validated in Singapore, a rapidly ageing multi-ethnic Asian country [11]. An initial qualitative study identified six critical QoL domains deemed important by local caregivers, namely physical, mental, social, spiritual and financial health, and daily life [12]. These were synthesized into five domains: Physical Well-being (PW), Mental Well-being (MW), Experience & Meaning (EM, including social and spiritual health), Impact on Daily Life (DL) and Financial Well-being (FW). Two short forms were created: the SCQOLS-10 (Supplementary Figure 1) and the SCQOLS-15 [13]. The former comprises 10 items (two from each domain), whereas the latter has 15 items, which include the 10 items of the SCQOLS-10. The SCQOLS-15 can assess both domain-specific and overall QoL levels of the respondent, while the SCQOLS-10 is recommended for evaluating overall QoL. The SCQOLS and its short forms are available in English, Chinese and Malay languages.

Despite being short and simple, the SCQOLS-10 provides an overall QoL score by capturing information across the five foundational domains. It is immediately ready to assess the QoL of Singapore informal caregivers without the need for cultural adaptation. However, preference weights are not currently available for any of the SCQOLS versions. Given its brevity, simplicity, comprehensive coverage, and availability in three languages, this study aimed to develop preference weights for the SCQOLS-10, establishing a culturally appropriate, caregiver-specific utility framework for direct application in health economic evaluations.

Methods

This study was approved by the Duke-NUS Departmental Ethics Review Committee (reference number: DERC-32-241021). It was a discrete choice experiment (DCE) with visual analogue scale (VAS) incorporated in an online cross-sectional survey [14-16]. This study adhered to the DIscrete choice experiment Reporting ChecklisT (DIRECT) for reporting of a discrete choice experiment [17] (Supplementary Table 1).

Survey and respondents

A survey research company was engaged to implement the survey and recruit respondents. Eligible respondents were recruited from the company's online panel, consisting of members residing in Singapore who have opted-in to participate in surveys.

In this study, an adult care-recipient was defined as either an adult (aged 21 years or above) patient with a chronic condition or an adult person who had no known chronic disease but was unable to practice self-care. An informal caregiver was identified as a person who (a) takes direct care of the day-to-day and healthcare needs of an adult care-recipient, (b) ensures provision of care to meet these needs, or (c) is the decision-maker regarding the meeting of these needs [11]. Respondents must be an informal caregiver currently or formerly in the past. Other eligibility criteria included: aged 21 years or above,

literate in English, and willing to provide informed consent. Individuals who were paid migrant domestic workers, who are commonly employed for caregiving duties in Singapore, were not eligible for participation.

A pilot study of 102 respondents was conducted. We evaluated the respondents' feedback and the time spent on answering the questions, which guided the questionnaire design in this study. We also estimated the proportion of respondents with illogical responses. A series of pilot analyses showed that in most occasions the estimated coefficients were in expected order.

The main survey was soft launched with 80 respondents to assess data quality, followed by a full launch. Initially, education level was classified into four categories, the highest being "*Post-secondary*". Preliminary data revealed that over 90% of soft launch respondents fell into this category. In the full launch, it was partitioned into 3 subcategories, "*Diploma & Professional Qualification*," "*Non-Tertiary*" and "*University or above*". Consequently, relevant soft launch respondents could only be classified under a broader "*Post-secondary (unclassified)*" category. Data from both soft and full launch phases were included in the final analysis.

Questionnaire

Eligible respondents self-administered an online anonymous English questionnaire, comprising questions on socio-demographics and caregiving information such as time spent on caregiving and caregiver role (sole caregiver or not). The care-recipient's performance status (CRPS), ranging from 0 (no physical limitation, without symptoms) to 4 (bedridden) indicating daily living ability, was also collected [18]. Moreover, the caregivers' QoL was assessed by the SCQOLS-10 and EQ-5D-5L [19]. Current caregivers were asked to assess their caregiving experience relative to "*the past seven days*", whereas former caregivers were instructed to recall "*a typical day of caregiving*". Since care-recipients may have no chronic disease, the phrase "*my sick family member*" was changed to "*my family member (I am taking care of)*" in three of the SCQOLS-10 items (MW2, EM11 and FW1).

In the VAS tasks, respondents were presented with six scenarios and asked to indicate how they rate their health if they were in the displayed hypothetical health state using the EQ-5D VAS (Figure 1a). Scenarios I to V (presented in a fixed order) described health states specified by the SCQOLS-10 items, whereas Scenario VI was "*Immediate death*". Since items are positively worded in the EM domain but negatively otherwise, the levels were recoded as 5 for the best level ("*Very much"* in EM and "*Not at all"* otherwise) and 1 for the worst. As such, the best health state can be represented by 55-55-55-55-55. Moreover, the rating was shown together with a smiley (happy, expressionless or sad face).

In the DCE section, there were seven choice tasks, each presenting a pair of scenarios defined by the SCQOLS-10 items (Figure 1b). Respondents were asked to choose their preferred scenario from each pair. To reduce potential cognitive burden, each item was rated on three levels only: "*Not at all*," "*Somewhat*" and "*Very much*" (corresponding to levels 1, 3 and 5 under the numbering described above), together with a smiley. The options of "*A little"* and "*Quite a lot*" (levels 2 and 4) were not presented. Their preference weights were subsequently obtained by interpolation. We further adopted an attribute-level overlap design: within each choice task, only five items (one from each domain) differed in level between the two scenarios, while the remaining five items were held at a common level. The overlap constraint was imposed during the generation of the Bayesian D-efficient design in Ngene software [20], and the items assigned to vary were rotated across 50 choice tasks. The first two choice tasks were comprehension questions. Only those who correctly answered them continued the survey. In this study, the 50 choice tasks were generated by a Bayesian D-efficient design and then divided into 10 blocks using Ngene software. Each respondent was randomly assigned one block containing five choice tasks. The order of the choice tasks and the left-right profile position of the two scenarios were fixed.

Development of preference weights

The DCE responses were fitted to a conditional logit model (CLM) with cluster-robust standard errors under a random utility framework [21,22]. The underlying function has the form:

$$U_{ij} = \sum_{k=1}^{10} \sum_{l=3,5} \beta_{kl} x_{ijkl} + \varepsilon_{ij}$$

where U_{ij} is the latent utility that respondent *i* would get from scenario *j*, x_{ijkl} are dummy variables for level l of item k, β_{kl} is the corresponding coefficient measuring the difference in utility from the reference level, and ε_{ij} is an error term. We employed a weighted analysis in which different weightings were assigned to the respondents according to their age, sex and education level for achieving a distribution closer to the profile in the two previous studies described below [11,23] and a recent survey of 4,500 caregivers conducted by Singapore's National Council of Social Service (NCSS) [24].

Twenty coefficients were estimated. Within each item, we verified whether $\beta_{k5} > \beta_{k3} > \beta_{k1} = 0$ as expected. Modifications by combining adjacent levels would be made if needed. The coefficients were converted to effect-coded and normalized to a DCE latent scale of which the sums for the best and worst states across all items equal 1 and 0, respectively. The DCE latent scale $\beta'_{kl}$was then anchored to death by rescaling to the dead-full health metric using a mapping approach [14-16]. The mean VAS score S_h for Scenario h was adjusted to a 0-1 scale:

$$S'_h = \frac{S_h - S_{VI}}{S_I - S_{VI}}$$

where S'_h is the VAS utility value for Scenario h, S_I and S_{VI} are the observed mean VAS for Scenarios I and VI, respectively. We regressed $(1 - S'_h)$ against $(1 - D_h)$ for Scenarios I to V in a no-intercept linear model, where D_h is the utility value of Scenario h defined on the DCE latent scale. The DCE latent scale was then mapped onto the dead-full health scale through $\alpha_{kl} = m\beta'_{kl}$, where m is the slope estimated from the linear model, resulting in preference weights for levels 1, 3 and 5. Preference weights for levels 2 and 4 were hence determined by interpolation: $\alpha_{k2} = (\alpha_{k1} + \alpha_{k3})/2$ and $\alpha_{k4} = (\alpha_{k3} + \alpha_{k5})/2$. Finally, given a health state, the SCQOLS utility value can be calculated as $\sum_k \alpha_{kl} + (1 - m)$, such that it equals to (i) 1 for the best state (55-55-55-55-55), (ii) 1 – m for the worst state (11-11-11-11-11), and (iii) 0 for death. Relative importance of each item was calculated as:

$$\text{Relative importance of item } k = \frac{\alpha_{k5} - \alpha_{k1}}{\sum_{\tilde{k}=1}^{10}(\alpha_{\tilde{k}5} - \alpha_{\tilde{k}1})} \times 100\%$$

Main analysis was performed using respondents without illogical responses (e.g. inconsistent QoL scores among different instruments, straight-lining in the SCQOLS-10, higher rating for worse or death states than better states in the VAS tasks). Sensitivity analysis was conducted to examine the robustness using (i) unweighted analysis, (ii) the full sample, (iii) respondents without illogical responses recruited from the full launch only.

Validation

The preference weights were applied to the responses to the SCQOLS-10 to compute the SCQOLS utility value. The sample distribution, floor and ceiling effects were examined. Respondents' SCQOLS and EQ-5D-5L (calculated using the Singapore value set) [25] utility values were regressed on caregiver role and CRPS adjusting for other variables. The coefficients were divided by the residual standard deviation (SD) to estimate the standardized effect size (SES), reflecting discriminative ability. The 95% confidence interval for the difference in SES was constructed using 1000 Bootstrap replicates and compared with a non-inferiority margin of 0.2 [26].

We also applied the preference weights to caregivers' responses from two previous SCQOLS studies: (a) Cancer study: 612 caregivers of cancer patients who completed the SCQOLS and the Brief Assessment Scale for Caregivers (BASC), with assessment of their CRPS [11]; (b) Heart disease study: 327 caregivers of heart disease patients who completed the SCQOLS-15 and BASC, with their care-recipient's health status rated by the New York Heart Association (NYHA) functional classification [23]. Known-group validity of the SCQOLS utility was assessed by comparing it against caregiver role and CRPS or NYHA functional classification. The BASC measures various aspects of caregiving experience, with a higher total score reflecting better caregiver outcomes [27], which is expected to be correlated positively with the SCQOLS utility. Concurrent validity was evaluated by its Pearson's correlation coefficients (r) with the BASC total score. Moreover, a subgroup of caregivers from these

studies who self-administered the questionnaire twice and reported a stable QoL were used to compute the intraclass correlation (ICC) for examining the test-retest reliability. All analyses were conducted using SAS OnDemand for Academics (version 9.4) [28].

Sample size determination

The sample size *N* was estimated using Ngene software by considering the S-estimate, which determines the minimum *N* required to ensure that all estimates are statistically significant [20]. In this study, the S-estimate for the Bayesian D-efficient design was 80. Since the 50 choice sets were distributed across 10 blocks, a minimum of 80 respondents per block was required, resulting $N = 800$. This sample size provided >80% power to detect differences in SCQOLS utility values between subgroups defined by their caregiver role and CRPS. Accounting for dropout due to illogical responses, we targeted to recruit 1000 respondents.

Results

Respondents

Among the 1036 eligible caregivers who completed the survey, 111 were excluded from the analysis due to illogical responses. The socio-demographics and caregiving characteristics of the remaining 925 respondents are summarized (Table 1 and Supplementary Table 2). Compared to the two previous SCQOLS studies [11,23] and the NCSS survey [24], there were more young, male and post-secondary educated caregivers in this sample. Therefore, in the analysis, respondents' weighting was assigned according to their age (40 years or below: 0.35, 41-64: 0.5, 65 or above: 0.15), sex (female: 0.6, male: 0.4) and education level (secondary or below: 0.35, post-secondary: 0.65). They spent a median of 1.38 (interquartile range = 1.00 to 2.04) minutes to answer the five DCE choice tasks, with 883 (95.5%) spending less than 5 minutes.

Development of SCQOLS preference weights

DCE data were fitted to a series of CLMs for the main and sensitivity analyses (Supplementary Table 3). In all models, the coefficients ordered in the expected direction for all items. Most differences between levels 1 and 3 and between levels 3 and 5 in the main analysis were statistically significant (p-values < 0.05; Table 2), with two exceptions: EM4 level 1 vs 3 (0.170, p-value = 0.102) and DL5 level 1 vs 3 (0.131, p-value = 0.121). Considering the moderate magnitudes, we left them as separate levels without combining. The coefficients were normalized to DCE latent scale and anchored to death by mapping to the VAS data.

Table 3 presents the mean (SD) and normalized VAS scores assigned by the respondents for each scenario. The utility values obtained from the DCE latent scale are computed. A no-intercept linear model resulted in a slope of 0.753. The DCE latent scale was rescaled to a dead-full health scale by multiplying 0.753, hence generating the SCQOLS preference weights for levels 1, 3 and 5 (Table 2, rightmost column). Finally, the weights for levels 2 and 4 were determined by interpolation.

The SCQOLS utility for a health state can be calculated as the sum of the relevant weight for each item-level and the constant 0.247. Equivalently, it is equal to 1 plus the sum of utility decrements from level 5, over all items (Supplementary Table 4). R and STATA codes for computing the SCQOLS utility can be found in Supplementary Material.

Figure 2 plots the utility decrement of each item-level and presents the relative importance of each item. PW6 *Poor appetite* (15.3%) had the largest relative importance, followed by the two items in the FW domain (FW3 *Uncertain financial situation* 14.5%, FW1 *Depletion of saving* 11.8%). On the other hand, PW4 *Aches and pains* (6.2%), EM11 *Closer family relationship* (6.6%) and DL5 *Unable to do what I want* (6.9%) were the least important items valued by the respondents.

Validation of SCQOLS utility

The SCQOLS utility was calculated for the 925 caregiver respondents based on the preference weights, together with the EQ-5D-5L utility. The SCQOLS utility had a mean (SD) of 0.730 (0.131), ranging between 0.378 and 1, with 14 (1.51%) respondents attained the maximum of 1. The EQ-5D-5L utility had a mean (SD) of 0.914 (0.144), ranging from –0.259 to 1, with 439 (47.5%) reported the maximum of 1 while 4 (0.43%) self-rated a negative utility. Current and former caregivers did not significantly differ in the mean of both measures (SCQOLS: 0.732 vs 0.725, p-value = 0.438; EQ-5D-5L: 0.911 vs 0.924, p-value = 0.208). The SCQOLS utility correlated moderately with the EQ-5D-5L utility (r = 0.307) and EQ-5D VAS (r = 0.402).

Table 4 shows the mean SCQOLS and EQ-5D-5L utility values for subgroups of caregivers stratified by caregiver role and CRPS. Both measures significantly detected the difference in caregiver role (both p-values < 0.01), but the SCQOLS utility also detected a significant trend in relation to the CRPS (p-value = 0.032), while the EQ-5D-5L did not (p-value = 0.141). Moreover, the SCQOLS utility obtained a larger point estimate in SES than the EQ-5D-5L utility in caregiver role (0.455 vs 0.277) and CRPS (0.071 vs 0.065). The lower limit of the 95% bootstrap confidence interval for difference in SES had a magnitude of 0.08 for both comparisons, smaller than the non-inferiority margin of 0.2.

The SCQOLS utility were also computed for caregivers recruited from two previous studies. It revealed a significant difference in caregiver role and trend in CRPS (both p-values < 0.001) in the cancer study (Supplementary Table 5). It also demonstrated a significant trend in NYHA functional classification in the heart disease study (p-value < 0.001), but did not show difference in caregiver role (p-value = 0.788). The SCQOLS utility strongly correlated with the BASC total score in the cancer (r = 0.729) and heart disease (r = 0.714) studies. Respectively 88 and 135 caregivers in these two studies were eligible for the assessment of test-retest reliability. The ICC was 0.846 in the cancer study and 0.821 in the heart disease study.

Discussion

We have developed the first preference weights for a QoL instrument conceptualized and designed from its inception specifically for caregivers in an Asian country. This facilitates local health economic evaluations in quantifying caregiver QoL without the need for cultural adaptation.

In health economic evaluations, health outcomes are often quantified using QALYs [9,10]. Computing QALYs requires a utility value scaled on the dead-full health (0-1) metric. The SCQOLS utility developed in this study is anchored to death, allowing for direct QALY calculations. In contrast, most commonly used preference-based caregiver-specific QoL instruments are not anchored to death. For example, a utility value of 0 indicates "*high unmet needs*" in the ASCOT-Carer [6,29,30], represents the "*worst informal care situation*" in the CarerQoL-7D [8,31,32], and serves as a baseline for the "*bottom caring state*" in the CES [7]. The utility values derived from them yield care-adjusted life years instead of standard QALYs. Hence, these metrics can only be used for comparison among caregivers but not direct cross-comparison with patient outcomes.

An exception is the Japan value set for the ASCOT-Carer [33]. The preference weights are anchored to death using the composite time trade-off (TTO) method. This value set yields a minimum utility value of 0.022. However, because caregivers are fundamentally healthy individuals, any observed QoL decrements stem primarily from caregiver-specific stressors such as fatigue, frustration, and the spillover effects from the care-recipient [34]. Furthermore, caregiving represents only one facet of a caregiver's life. Even when the caregiving experience is deeply negative, other personal domains often provide positive utility. Consequently, it is implausible that a caregiver's overall QoL would ever drop to a level nearly indistinguishable from death. In comparison, the SCQOLS utility has a minimum of 0.247, offering a more realistic reflection of caregiver well-being.

The conceptual scope of these instruments varies considerably. The CarerQoL-7D covers all six domains deemed important by Singapore caregivers [8]. However, its existing value sets were developed exclusively in Western populations, who prioritize these domains differently. The "*Mental health problems*" item in the CarerQoL-7D shows a larger relative importance than "*Financial problems*" in all evaluated countries except Germany [31,32]. Conversely, in the SCQOLS-10, the two FW items (FW1: 11.8%, FW3: 14.5%) demonstrated greater relative importance than the two MW

items (MW2: 8.8%, MW8: 11.1%). The pronounced importance of the FW items may reflect the structural nature of Singapore's healthcare financing system, which relies heavily on individual co-payments, medical insurance and/or health savings accounts. These financial concerns are also relevant to countries where self-payment constitutes a major component of healthcare funding. Moreover, "*Physical health problems*" in the CarerQoL-7D ranks among the top three dimensions (15.1% to 23.0%). Its closest counterpart in the SCQOLS-10, PW4 *Aches and pains*, emerged as the least important item (6.2%). Interestingly, the other PW item, PW6 *Poor appetite*, was valued as the most important (15.3%), yet this symptom is unassessed by the CarerQoL-7D. The ASCOT-Carer and CES focus predominantly on daily life and social or spiritual health, but they have no items assessing mental and financial health [7, 8]. Therefore, they may still lack the conceptual suitability required for broader application in Asia [33]. Taken together, these discrepancies highlight distinct cultural and policy differences in caregiving experiences between Western and Eastern populations, underscoring the necessity of using a culturally appropriate instrument.

The SCQOLS utility demonstrated a mild ceiling effect of 1.51%, compared to nearly half (47.5%) for the EQ-5D-5L utility. Moreover, no respondent reached the minimum SCQOLS utility of 0.247, whereas 4 respondents reported a negative EQ-5D-5L utility. As noted above, it is implausible for a caregiver's QoL to drop below a worse-than-death level. We further compared the discriminative ability between the two instruments. Both utility values detected statistically significant difference in relation to caregiver role, but the SCQOLS utility obtained a larger SES. Although superiority could not be established, the SCQOLS utility was demonstrated to be non-inferior to the EQ-5D-5L utility in this regard. Nevertheless, despite the widespread use of EQ-5D in various populations including caregivers [34,35], this comparison may be conceptually misaligned as it is a generic instrument designed to assess patient health status. Furthermore, the SCQOLS utility demonstrated strong concurrent validity and satisfactory test-retest reliability.

In health preference research, direct valuation methods such as the TTO are frequently used for utility elicitation [36,37], but they may be conceptually inappropriate for the valuation of caregiving. Because caregiving is not a life-threatening condition under normal circumstances, a caregiver's survival time

and immediate mortality risks are unlikely to be affected in the foreseeable future. Consequently, respondents may be reluctant to trade life-years, making these techniques nonsensical in this context. Methodologically, DCE and VAS are highly intuitive, easily understood by respondents, and seamlessly integrated into an online survey infrastructure [38-40]. While a universal gold standard method for anchoring has yet to be established, the DCE-VAS approach utilized in this study has been successfully implemented in several valuation studies [14-16].

This study has limitations. First, the sample skewed younger and more educated than cohorts in previous studies [11,23,24]. Second, online surveys introduce challenges in monitoring participant engagement. Consequently, we could not establish the underlying mechanisms of illogical responses. To mitigate potential bias, we performed sensitivity analyses. The consistent results across these alternative models suggest that data quality did not compromise the validity of the DCE tasks. Another limitation is the interpolation of levels 2 and 4. Although interpolation typically applies to numeric attributes in DCE research [41,42], it is also applicable to ordinal attributes like pain severity scale [43], frequency and degree of limitations [44]. In this study, the coefficients demonstrated an expected monotonic trend across all items, with interpolation yielding smooth utility decrements. We expect that the preference weights for levels 2 and 4 would not deviate substantially if all five levels had been evaluated.

In conclusion, we developed the first preference weights for the SCQOLS, an instrument designed to measure QoL among caregivers in Singapore. By providing a culturally appropriate framework, the value set facilitates future health economic evaluations of caregiver QoL, ultimately supporting healthcare decision-making and resource allocation. With the availability of multiple language versions, especially English and Chinese which are two of the most widely used languages worldwide, the SCQOLS utility may have potential applications in other countries.

List of abbreviations:

ASCOT-Carer, Adult Social Care Outcomes Toolkit for Carers

BASC, Brief Assessment Scale for Caregivers

CES, Carer Experience Scale

CLM, Conditional logit model

CRPS, Care-recipient's performance status

DCE, Discrete Choice Experiment

DIRECT, DIscrete choice experiment Reporting ChecklisT

DL, Impact on Daily Life

EM, Experience & Meaning

FW, Financial Well-being

ICC, Intraclass correlation

MW, Mental Well-being

NCSS, National Council of Social Service

NYHA, New York Heart Association

PW, Physical Well-being

QALY, Quality-adjusted life year

QoL, Quality of life

SCQOLS, Singapore Caregiver Quality Of Life Scale

SD, Standard deviation

SES, Standardized effect size

TTO, Time trade-off

VAS, Visual Analog Scale

Declarations

Ethics approval and consent to participate

This study was approved by the Duke-NUS Departmental Ethics Review Committee (reference number: DERC-32-241021). Eligible respondents were recruited from a survey research company's online panel who have opted-in to participate in surveys.

Consent for publication

Not applicable

Availability of data and materials

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

Competing Interest

The authors declare no financial and non-financial competing interest.

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Authors' contributions

CFL, MG, SK, SS and YBC conceived and designed the study. CFL, SK, SS and YBC developed the DCE and VAS tasks and the survey questionnaire. CFL performed statistical analysis and drafted the first version of the manuscript. All authors participated in critical review and revision of the manuscript and approve the submission.

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Table 1. Socio-demographics and caregiving information of the 925 respondents

Characteristics	Mean (SD) / N (%)
Age of respondent (years)	38.6 (10.5)
Sex	
Female	479 (51.8%)
Male	446 (48.2%)
Ethnicity	
Chinese	687 (74.3%)
Malay	175 (18.9%)
Indian	48 (5.2%)
Others	15 (1.6%)
Education level	
Secondary or below	78 (8.4%)
Post-secondary	
Diploma & Professional Qualification	273 (29.5%)
Non-tertiary	137 (14.8%)
University or above	367 (39.7%)
Unclassified	70 (7.6%)
Marital status	
Married	637 (68.9%)
Single	256 (27.7%)
Divorced / Widowed	32 (3.5%)
Employment	
Working, full-time	776 (83.9%)
Working, part-time	84 (9.1%)
Unemployed / Retired / Student / Others	65 (7.0%)
Monthly household income (Singapore dollar, S$)	
< S$6,000	134 (14.5%)
S$6,000 to < 8,000	100 (10.8%)
S$8,000 to < 10,000	109 (11.8%)
S$10,000 to < 15,000	229 (24.8%)
S$15,000 to < 20,000	202 (21.8%)
S$20,000 to < 25,000	100 (10.8%)
S$25,000 or above	51 (5.5%)
House type	
Housing and Development Board 1-/2-room	36 (3.9%)
Housing and Development Board 3-/4-room	424 (45.8%)
Housing and Development Board 5-room or more	234 (25.3%)
Condominium / Bungalow / Others	231 (25.0%)
Caregiver role	
Only person	227 (24.5%)
Primary person	412 (44.5%)
One of a few persons	286 (30.9%)
Care-recipient's performance status	
0	79 (8.5%)
1	328 (35.5%)
2	278 (30.1%)
3	179 (19.4%)
4	61 (6.6%)

Table 2. Effect-coded coefficients, normalized to Discrete Choice Experiment (DCE) latent scale and rescaled to dead-full health metric

Item / level	Coefficient (standard error)	Difference†	DCE latent scale (β'_{kl})	Dead-full health scale (α_{kl})
PW4 Aches and pains				
Level 5: Not at all	0.259 (0.056)		0.081	0.061
Level 3: Somewhat	–0.017 (0.059)	0.276**	0.047	0.035
Level 1: Very much	–0.242 (0.060)	0.225*	0.019	0.014
PW6 Poor appetite				
Level 5: Not at all	0.578 (0.057)		0.121	0.091
Level 3: Somewhat	0.075 (0.063)	0.503**	0.058	0.044
Level 1: Very much	–0.653 (0.054)	0.728**	–0.032	–0.024
MW2 Fearful of losing family member				
Level 5: Not at all	0.415 (0.062)		0.100	0.076
Level 3: Somewhat	–0.116 (0.062)	0.530**	0.035	0.026
Level 1: Very much	–0.299 (0.054)	0.183*	0.012	0.009
MW8 Feeling of frustration				
Level 5: Not at all	0.467 (0.058)		0.107	0.081
Level 3: Somewhat	–0.040 (0.054)	0.508**	0.044	0.033
Level 1: Very much	–0.427 (0.058)	0.387**	–0.004	–0.003
EM4 Thankful for good things				
Level 5: Very much	0.279 (0.058)		0.084	0.063
Level 3: Somewhat	0.109 (0.058)	0.170	0.063	0.047
Level 1: Not at all	–0.389 (0.053)	0.498*	0.001	0.001
EM11 Closer family relationship				
Level 5: Very much	0.289 (0.059)		0.085	0.064
Level 3: Somewhat	–0.043 (0.058)	0.331**	0.044	0.033
Level 1: Not at all	–0.246 (0.059)	0.204*	0.018	0.014
DL2 Unable to leave home/hospital				
Level 5: Not at all	0.467 (0.053)		0.107	0.081
Level 3: Somewhat	–0.099 (0.058)	0.566**	0.037	0.028
Level 1: Very much	–0.368 (0.065)	0.269*	0.003	0.002
DL5 Unable to do what I want				
Level 5: Not at all	0.327 (0.054)		0.090	0.067
Level 3: Somewhat	–0.098 (0.064)	0.425**	0.037	0.028
Level 1: Very much	–0.229 (0.051)	0.131	0.021	0.015
FW1 Depletion of saving				
Level 5: Not at all	0.453 (0.060)		0.105	0.079
Level 3: Somewhat	0.046 (0.055)	0.407**	0.055	0.041
Level 1: Very much	–0.499 (0.060)	0.544**	–0.013	–0.010
FW3 Uncertain financial situation				
Level 5: Not at all	0.579 (0.055)		0.121	0.091
Level 3: Somewhat	0.014 (0.056)	0.564**	0.051	0.038
Level 1: Very much	–0.593 (0.063)	0.607**	–0.025	–0.019

† Level 5 minus Level 3 and Level 3 minus Level 1

* P-value < 0.05

** P-value < 0.01

Table 3. Visual Analogue Scale (VAS) and utility of six hypothetical health states

Scenario	Health state	Mean VAS (SD)	Normalized VAS	DCE latent utility	Rescaled to dead-full health metric
I	55-55-55-55-55	85.7 (10.2)	1	1	1
II	35-35-33-53-53	71.9 (11.1)	0.819	0.715	0.784
III	33-33-33-33-33	57.1 (12.8)	0.626	0.469	0.599
IV	31-31-33-31-31	42.1 (15.9)	0.431	0.239	0.425
V	11-11-11-11-11	26.0 (18.1)	0.220	0.000	0.246
VI	Immediate death	9.2 (14.0)	0		0

Table 4. Discriminative ability of the SCQOLS utility and head-to-head comparison with the EQ-5D-5L utility

		SCQOLS utility			EQ-5D-5L utility			Difference in SES
Grouping factor	N	Mean (SD)	P-value	SES	Mean (SD)	P-value	SES	(95% Bootstrap CI)
Caregiver role								
The only person	227	0.711 (0.123)	0.009†	0.455	0.887 (0.173)	0.005†	0.277	0.179 (–0.080 to 0.420)
One of a few persons	698	0.737 (0.133)			0.923 (0.132)			
Care-receiver's performance status								
0	79	0.757 (0.131)	0.032‡	0.071	0.932 (0.094)	0.141‡	0.065	0.006 (–0.080 to 0.098)
1	328	0.729 (0.131)			0.921 (0.120)			
2	278	0.730 (0.129)			0.899 (0.186)			
3	179	0.737 (0.130)			0.926 (0.107)			
4	61	0.684 (0.137)			0.891 (0.179)			

Abbreviations: SD, standard deviation; SES, standardized effect size; CI, confidence interval.

† Two-sample t-test

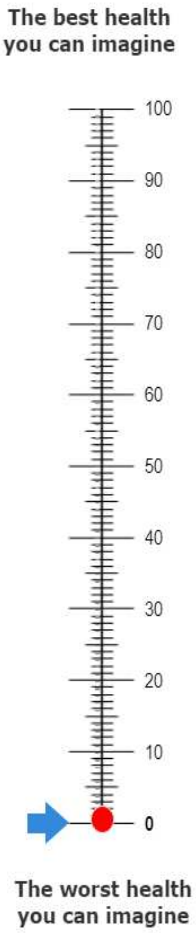
‡ Non-parametric test for trend

Figure 1. Example of (a) Visual Analogue Scale (VAS) and (b) Discrete Choice Experiment (DCE) tasks

(a)

How do you rate Scenario II?

Item label	Description	Scenario II
Aches and pains	I have had more aches and pains due to caregiving activities	Somewhat
Poor appetite	My appetite is poor	Not at all
Fearful of losing family member	I am fearful of losing my family member I am taking care of	Somewhat
Feeling of frustration	I feel frustrated	Not at all
Thankful for good things	I am thankful for the good things that have happened to me even in difficult times	Somewhat
Closer family relationship	Caring for my family member has drawn the family closer together	Somewhat
Unable to leave home/hospital	I am bothered that I am not able to leave home or hospital	Not at all
Unable to do what I want	I am not able to do what I want to do	Somewhat
Depletion of saving	I am troubled that my family member's condition is depleting my savings	Not at all
Uncertain financial situation	I feel uncertain about my future financial situation	Somewhat

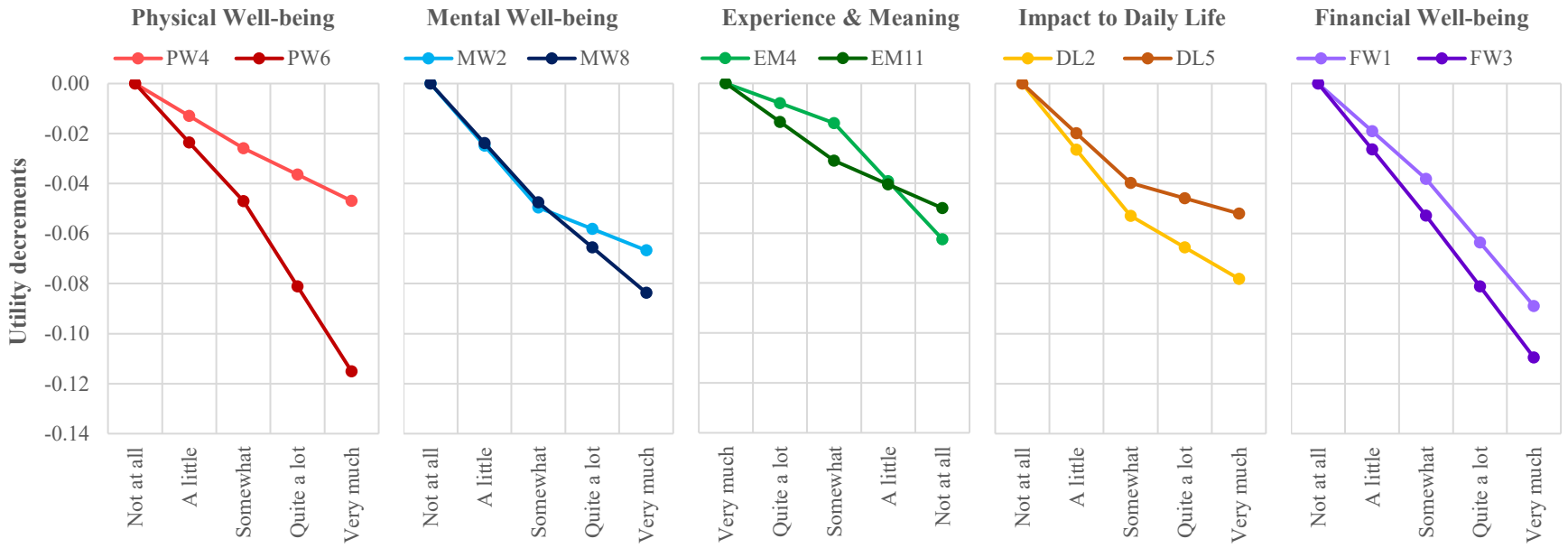


(b) **Which scenario is the better one?**

Please indicate at the bottom which scenario is the better one you prefer.

Item label (hover to view full descriptions)	Scenario A	Scenario B
Aches and pains	Not at all	Somewhat
Poor appetite	Not at all	
Fearful of losing family member	Not at all	Very much
Feeling of frustration	Somewhat	
Thankful for good things	Somewhat	Very much
Closer family relationship	Very much	
Unable to leave home/hospital	Somewhat	Very much
Unable to do what I want	Not at all	
Depletion of saving	Somewhat	Not at all
Uncertain financial situation	Not at all	
Which scenario do you prefer?	●	●

Figure 2. Utility decrement and relative importance for each item



Response	PW4	PW6	MW2	MW8	EM4	EM11	DL2	DL5	FW1	FW3
Not at all	0	0	0	0	–0.062	–0.050	0	0	0	0
A little	–0.013	–0.024	–0.025	–0.024	–0.039	–0.040	–0.026	–0.020	–0.019	–0.026
Somewhat	–0.026	–0.047	–0.050	–0.047	–0.016	–0.031	–0.053	–0.040	–0.038	–0.053
Quite a lot	–0.036	–0.081	–0.058	–0.066	–0.008	–0.015	–0.065	–0.046	–0.064	–0.081
Very much	–0.047	–0.115	–0.067	–0.084	0	0	–0.078	–0.052	–0.089	–0.110
Relative Importance	6.2%	15.3%	8.8%	11.1%	8.3%	6.6%	10.4%	6.9%	11.8%	14.5%

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