Assessment of Health-Related Quality of Life in Palliative Home Healthcare Elderly Patients

P. Gonghom
Golden Jubilee Medical Center,
Faculty of Medicine, Siriraj Hospital,
Mahidol University, Salaya, Thailand

K. Tantivitayatan[*]
Golden Jubilee Medical Center,
Faculty of Medicine, Siriraj Hospital,
Mahidol University, Salaya, Thailand

S. Siriwattanakul
Golden Jubilee Medical Center,
Faculty of Medicine, Siriraj Hospital,
Mahidol University, Salaya, Thailand

M. Rattasompattikul
Golden Jubilee Medical Center,
Faculty of Medicine, Siriraj Hospital,
Mahidol University, Salaya, Thailand

Abstract: Quality of Life (QoL) is essential in palliative care, especially for non-communicable, terminal patients, that it needs a valid and reliable instrument. The QoL for Late-Stage Dementia (QUALID) could be applied to this patient group with our study on the Thai translated version to have Cronbachs alpha 0.627. The Home Health Care Division, Golden Jubilee Medical Center, has ongoing research with the primary objective of its efficiency on 21 palliative adult patients at home during 2018-19. The median age was 83 years old (63-95), female: male 1.1:1, baseline QUALID assessment rate 100% with median 25 (13-41). The subsequent scores were 27.5 and 19, guiding physical, mental, and spiritual care, while the family satisfaction scored at the good to the best level. More than 80% of the patients passed away during the study. This interim report describes QUALID as a model of Item Response Theory (IRT), which supports that the translated QUALID was acceptably valid and reliable in guiding palliative terminal care at home.

Keywords: QoL, QUALID, Palliative Terminal Care, IRT

I. INTRODUCTION

Despite various definitions of QoL, the general one is that QoL is multidimensional, subjective, and dynamic [1]. For Health-Related QoL (HRQoL), it is an individuals or groups perception over time pertaining to healthcare such as health status, emotional well-being, and treatment satisfaction [1, 2]. QoL (in the sense of HRQoL) assessment has become a measure of interest in improving clinical care, especially for palliative terminal patients, because it should be impeccable as defined by WHO [3] sparsely remains a chance for correcting any wrongdoing. The best way is to self-assess or Patient-Reported Outcomes (PRO) [4, 5, 6], which can be done either qual-

itatively or quantitatively [1], but most patients at the end of life have poor or even non-communicability posing a significant obstacle to obtain an accurate and informative assessment. QUALID is one among various tools for QoL assessment, and we have tried it for a few years previously on terminally ill, uncommunicable patients both hospitalized and cared at home, finding it working also in this group. The questionnaire has 11 items, grading emotions and behaviours on 5 score levels; for example, Smiles: 1) spontaneously once or more each day 2) spontaneously less than once a day 3) only in response to external stimuli; at less, once a day 4) only in response to external stimuli; less than once a day and 5) rarely, if at

all. The scores are summed as a total ranging from 11 to 55, with lower scores representing higher QoL [7, 8, 9]. Thus the score polarity has a spectrum approximated as good, fair, and poor QoL. Another remarkable feature includes a proxy assessment by the same caregiver who stays close with the patient for at least 3 days a week. Under the permission of the copyright owner, Dr. Weiner, we translated into the Thai language. We co-studied its psychometric property like validity and reliability with the Psychology Department, Siriraj Hospital, revealing a Cronbachs alpha to be acceptably 0.627 - slightly less than the original English version [7, 10, 11, 12]. The current study focuses on its use as a clinical guide for higher QoL, such as prescribing oral morphine sulphate for distress relief, social and spiritual care, especially in patients dying at home; thus, the main objective is to study the efficiency of QUALID in-home palliative care. This 1-year interim report, in addition to monitoring the research progress, presented problems and how to refine the study's conduct.

II. METHODS

After Ethics approval, for a study during October 2018- September 2020, the number of patients was calculated to be 74 with a 20% dropout. The inclusion criteria were adult, terminally ill, uncommunicable patients on home palliative care with either cancer or non-cancer; their caregivers, who would be informed and consent obtained, were literate in the Thai language and looked after the patients at least 3 days a week for a minimum of 1 month. QUALID consists of 11 questions with 5 answers and total scores ranging from a minimum 11 to a maximum 55, of which 11-17 would be rated as poor QoL,18-28 fair, and 29-55 good [13]. The patients were assessed as baseline QUALID scores at the first visit and then reassessed every month or when any situation could impact their QoL. Clinicians would use the score to help guide how to palliatively care, aiming for a good QoL, like titrating up oral morphine dose, appreciative dialogue to enhance self-esteem, social participation, etc. Data were collected about the patients characteristics, several deaths, initial and later QUALID scores, and caregivers satisfaction. Parametric statistics were used as appropriate.

III. RESULTS

Within 1 year, a half-period of the study, 21 terminal patients at home were studied, as reflected in Table 1.

TABLE 1
PATIENTS' CHARACTERISTICS ($N = 21$)

Age (years):	
Median	83
Range	63-95
Gender F: M 1.1: 1 Diseases:	
Cancer	1
Non-cancer e.g., Parkinsons, End-stage renal	20
Mobility: bed-ridden	100%
Baseline QUALID scores:	
Median	25
Range	13-41
Number of assessments (times):	
2	8
3	5*
> 3	2
Living status:	
Alive	2
Dead	19

NB: 2nd time redundant assessments in 2 patients, including 1 outlier.

There were missing data about ages in 5 records of 2 female and 3 male patients; mobility was controversial in 1 patient due to illness instability. One caregiver was Myanmar, who spoke the Thai language and contributed to the assessment while the rest were Thai. Baseline QUALIDs were assessed 100%, while 8 of 21 patients (38%) could be reassessed for the second time and 23% for the third. The frequency of assessments could be obtained every month in 6 patients, while the longest interval was 2 months. It was found that QUALID could be assessed in both paper and electronic forms, which caused redundant data in 3 patients. The outlier was 1 patient

scoring 6, which was less than a QUALID minimum of 11. The median baseline scores were 25 and 24.5, with the outlier and without, respectively. The overall picture of QUALID assessments was depicted in Fig. 1. Over 80% of the patients passed away during the period, after which the families satisfaction with the home visit services was good to excellent. The trends of the scores were shown in Fig. 2, and the medians of baseline, 2nd, and 3rd time assessments were 25, 27.5, and 19. With QUALID scores 17-28 as a continuum between two extreme QoL polarities, those toward 11 counted for the good 24% while the fair and the poor toward 55 were 47% and 29% as a baseline. The second and third-time assessments scored well, only 1 and 2 patients, respectively.
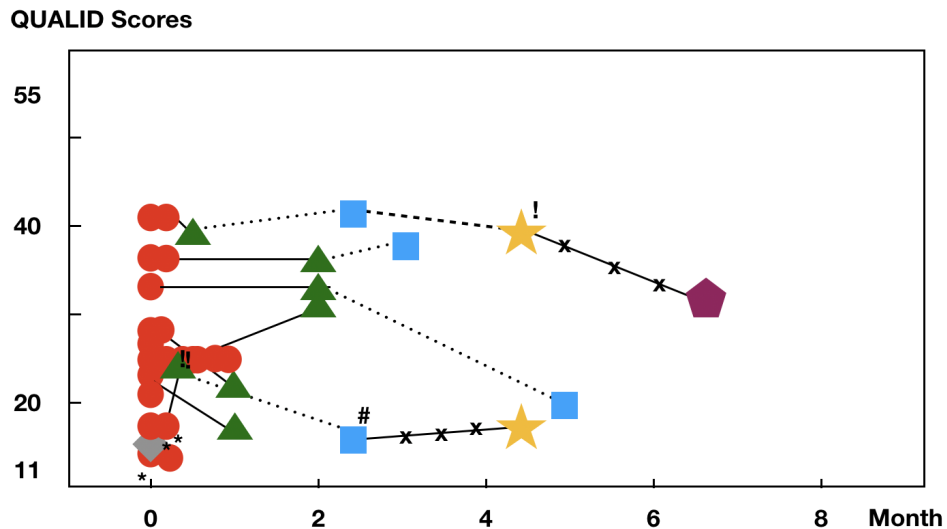

Fig. 1. The overall picture of QUALIDS trends in 21 patients over a 1-year period of the study: Baseline, 2nd, 3rd, 4th, and 5th assessments were represented as a circular, triangular, square, star, and pentagonal shapes, respectively
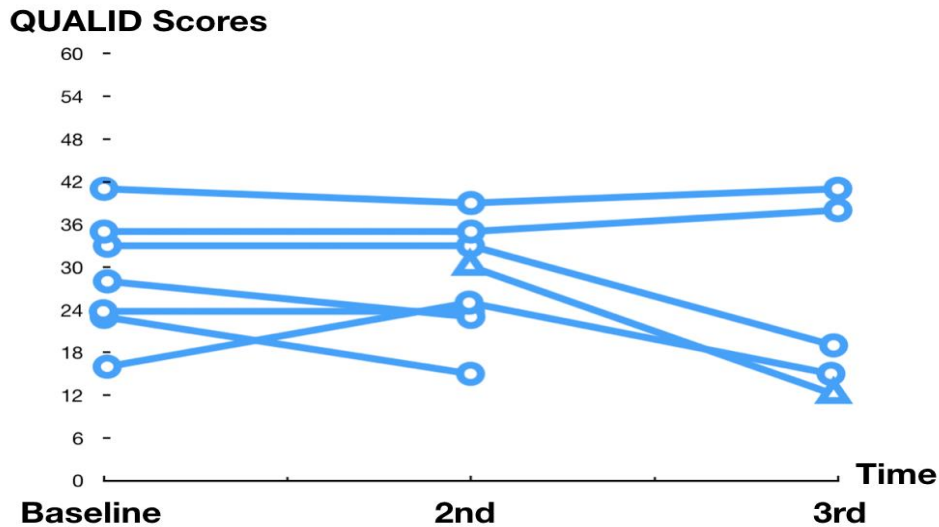

Fig. 2. The trends of assessment scores 3 times with adjusted time intervals
NB: the triangular shapes represent the outlier with an excluded baseline assessment

IV. DISCUSSION

QoL is the term of interest since Aristotle (384-322 BCE) and has become a familiar term that, even without a need for further explanation at this time, should cover human experiences, states, perceptions, and mindset about the life of an individual or a community [4]. QoL implies a judgment of value placed on experiences of either. HRQoL came later with the WHO definition of health in 1948 as a state of well-being in 3 dimensions, namely physical, psychological, and social, in the context of disease. HRQoL includes both objective clinical outcome measures such as cure, biological response to treatment, survival, and subjective indicators such as PRO, QoL- emotional, physical, social functioning, pain, fatigue, other symptoms, and toxicity. Therefore QoL concerning health could be measured qualitatively and quantitatively.
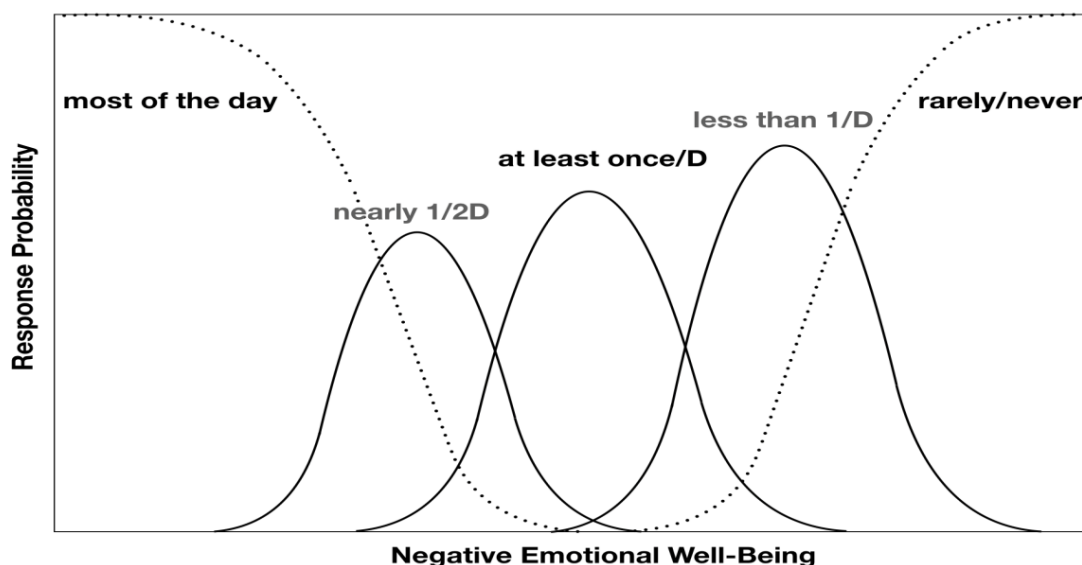

Fig. 3. A 5-option response to one item of interest - negative emotion well-being e.g., crying, to reflect QoL on a continuum from most of the day (the unable in the sense of goof QoL) to rarely/never (the able)

Quantitatively measuring an abstract construct such as QoL is very difficult; the usual method is classical or true score like a numeric scale 1-10 or even a better one is factor analysis either exploratory or confirmatory by assessment of items of interest in Likert tiers [14]. Problems arise when these scores' sums are equal between the two does not mean their abilities are the same. The modern approach, IRT, makes for the variation of abilities in response to each item so that the information gained can explain difficulty and discrimination between the able versus the unable, as reflected in Figure 3. The sums of scores can infer some differences between the two examinees, such as likelihood function and other properties derived from Item Characteristic Curves (ICC): item information, test information, and reliability, which is better than the classic Cronbachs alpha [13]. Accumulation of data in IRT helps build an item bank, that will refine each item's precision in the future.

The goal of measurement is to achieve the highest quality data and the lowest error influenced by an assessor and the interface between her and an instrument. The QUALID studied was assessed by the patients relatives or caregivers who varied in linguistic intelligence, especially from other nationalities. IRT depends on understanding and attitude in response to each item question [13]. The scoring via electronic system also depends on technology intelligence, thus creating redundant or anomalous data. The assessments were mostly discontinued for the second time by the patients passing away. The outlier occurred in the semi-comatose patient with such an expressionless face that some questions could not be assessed. The baseline scores were toward fair and poor QoL; the justified reason for the study of how the instrument would guide the palliative terminal care for a better QoL. The trend in subsequent assessments did not reveal any betterment, and one important lesson learned was the varied understanding about relief processes and medications in end-of-life care - almost all the relatives abstained from the morphine use for fear of its addiction hastening the death of their loved ones. Although the family meeting for the palliative care plan was obliged before starting the terminal care and when the time came, the relatives could not let go but brought the patients to the hospital with some dying during the transfer. For the care providers,

poor QUALID scores would guide increasing morphine both in dosage and frequency, of which the advice was not sometimes followed. The low social item response would trigger the idea of fetching siblings or subordinates to visit. Missing data could be corrected with data in electronic medical records.

Palliative care runs parallel with (or behind) curative care; the former focuses on relieving symptoms and suffering - QoL for each day, while the latter on causes of illness and survival - prolonging living days. Thus QoL assessment is crucial for a patient at the end of life to fill in any last and never again happiness to complete as a good life. Since almost all cannot communicate verbally, a reliable instrument to probe their wants is needed. This interim analysis could not prove that QUALID was better than other measuring instruments, probably because the sample size was not yet enough. The theoretical benefits were described, and practical advantages were gained from the caregivers who did the same assessments, and if by virtue of item bank, the instrument could lessen the item number and burden of responsibility. Other assessment instruments are used by a nurse who is likely to change in shift, spending less time with the patient than the caregiver. QUALID numeric scores are useful in comparing quality care between individuals and overall QoL indicators of care among healthcare entities. Most questions are asked, in addition to physical, in an emotional domain e.g., when friends come, the patient smiles, has some response or not at all, which is another comprehensive core component in palliative care besides spiritual, social, and financial domains. Palliative care has many influential factors on QoL like spiritual care, which is profound in the concept of mind-body control.

A. Suggestions to Conduct the Rest of the Study

- No need for protocol amendment, add the specific detail to the study process i.e., emphasizing knowledge management on everyone involved in a family meeting, considering storytelling of similar cases for learning and anticipation any worst scenarios, assessment of caregivers in terms of Thai language intelligence

- More stringent on the QUALID assessment and re-assessment schedule

This report raised relevant issues for a further study like QoLs between equal combined scores, reliability between IRT versus Cronbachs in the translated QUALID, etc.

V. CONCLUSION

Measurement of a latent construct, QoL, could be approached by classic and modern methods. QUALID is an IRT model that can inform as close as facts via items of interest for an individual and a comparison. The translated Thai version has an acceptable consistency and reliability; this interim report revealed a certain gap for improvement before finishing the study, addressing the assessment process and forms. This QUALID study supported the benefits of IRT, and further considerations suggested.

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