Quality of Life Assessment in Palliative Stage Cancer Patients

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Abstract

Indicators of success in oncology traditionally include cure, survival, and tumor response. In advanced stage however, Quality of life (QOL) has become an important outcomes.[10, 12] Despite the broad use of the term QOL, it is difficult precisely define.[10,12] It is multidimensional, dynamic and subjective concept.[3, 5, 10] The numerous questionnaire for QOL measurement lead to a challenge for its application.[12] Most of QOL instrument include physical symptoms, functioning, psychological and social well-being.[12] In advanced stage existential, meaning, fulfillment, purpose and grief become more prominent.[11, 12] Besides the contain of the questionnaire, validity and reliability need to be considered in deciding which instrument will be applied.[12]

This paper discusses the definition of QOL, the purpose of measuring QOL, various QOL instruments, the McGill Quality of Life Questionnaire as a measure suggested in clinical practice and the reasons for its application.

***Key words**; Quality of Life, Palliative, Cancer Patients*

Abstrak

Indikator keberhasilan tatalaksana dalam onkologi adalah penyembuhan, harapan hidup dan respon tumor. Kualitas hidup pada kanker stadium lanjut menjadi faktor penting. Terminologi kualitas hidup sulit didefinisikan karena multidimensi, dinamik dan konsep yang subjektif. Berbagai jenis kuesioner untuk pengukuran kualitas hidup mengakibatkan tantangan cukup besar untuk penerapannya. Sebagian besar intrumen kualitas hidup termasuk gejala klinis, fungsi, psikologis dan kehidupan sosial. Kebutuhan akan makna hidup, harapan dan kedukaan pada pasien stadium lanjut menjadi meningkat.

Oleh karena itu validitas dan realibitas harus dipertimbangkan bila menetapkan instrumen yang akan digunakan. McGill kuesioner sebagai pengukuran kualitas hidup dapat disarankan untuk digunakan dalam praktek klinis.

Kata Kunci : Kualitas hidup, Palliatif, Pasien kanker.

Introduction

The concept of QOL is multidimensional, dynamic, patient centered and subjective.[3, 5,10] One of the definitions is the physical, psychological, social and spiritual domains of health that are influenced by a person experience, belief, expectation and perception. In patients with advanced stage, it is difficult to precisely define and to measure.[10,12] Cohen identified the broad domains of QOL according to the patients perspective which include own state, quality of palliative care, physical environment, relationship and outlook. It is still unsure, however, about how patients with terminal illness perceived their life. They may adjust their standard of QOL.[15] What is important and how they weight the components of life may change. Something other than physical status is possible to become a source to reach a good QOL. Factors that contribute to a QOL may not be obvious but they can have a great impact. Patients with sign of physical or psychological limitation may report a high degree of QOL. In time remaining to patients with a limited prognosis, spiritual domains such as meaning, existential, and purpose take on a greatly importance.[6] Spiritual helps people continue to value themselves and their life.[2] The dynamic and subjectivity of QOL can be shown that aspect which essential to one person may mean not important to another or may become less important in the next day.

Patient's report is the gold standard in QOL assessment.[3,15] However, there are particular concerns about the use and relevance of outcome measures of quality of life in palliative care as the patient may be very sick or having communication deficit so that unable to answer the question, or severely distress due to the

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symptoms or cognitively impaired so that may impede the process.[5] Some patients may wish to play down the symptoms to avoid certain treatment or hospitalization. In the opposite way, they may exaggerate symptoms to escape from intolerable situation.[15] Self report can be supplemented by professionals or caregiver's report. However, it is reported that health staff and caregivers are poor estimators so it leads to potential bias.[15]

The purpose of measuring QOL

QOL is one of patient-centered outcome that can be seen as the result of intervention.[15]

Measuring QOL enables us to: [9, 15]

- Identify multidimensional aspects along the disease trajectory
- Describe the patients' problems and needs for clinical monitoring
- Audit care provided
- Assess efficacy of service
- Identify the potential area for improvement
- Elicit preference to assist with decision making
- Inform purchasers and secure resources
- Facilitate a good communication and rapport

QOL tools that have been validated and commonly used in patients with advanced stage

A number of QOL instruments have been designed. However, none of them is considered ideal for palliative care patients.[11] The QOL tools found through CINHL searching includes: McGill Quality of Life Questionnaire (MQOL), Client Generated Index (CGI), City of Hope Model, QOL Model of Ferrean and Power, Schedule for Evaluation of Individual QOL (SEIQOL), Study Short Form (SSF), Functional Assessment of Cancer Treatment for Colorectal (FACT-C), European Organization for Research on Cancer Treatment (EORCT-C30), Impact of Event Scale (IES), Rotterdam Symptom Checklist and Activities of daily Living (ADL)

Most QOL instruments are not specifically designed for or have not been tested in palliative care.[8] They specifically address physical symptoms, performance status, the presence of anxiety and depression and social support and/or social functioning.[1,2,7] They do not adequately cover the essential domain such as perception of purpose, meaning in life and the capacity for personal growth and transcendence which become more dominant for patients with a life-threatening illness.[1,7] Some of QOL instruments are excessively focused on physical domain. The long lists of symptoms that may include irrelevant symptoms lead to lengthy duration of measurement, which is inappropriate for patients with limited physical and cognitive.[1] Another identified shortcoming of most instruments is compiling a list of problem but not measuring positive contributions to QOL.[1]

MQOL and why MQOL

MQOL was developed by Cohen et al in Canada and specifically designed for patients in palliative stage.[8,11] It is one of the most broadly used instrument to measure quality of life in palliative care. The items in the questionnaire are derived from patient interviews, literature review and existing instruments.[7] It seems potentially to become the best tool to meet the essential criteria of QOL in palliative care.[8] The first version of MQOL reported in 1995 contained 17 questions.[1,9] However, question number 10 (I feel close to people) was eliminated in MQOL version 1996, as the question was not clear and difficult to interpret.[1] The version used in this paper is as the scale appears in Cohen et al, 1996, consists of 16 items.[15,16] The instrument uses open ended question about issues that have impact on a patient's QOL. Physical symptoms are self-identified. Patients are asked to score their conditions within the last two days, using an[11] categorial rating scale (0-10), with the extremes of least desirable and most desirable at the either end.[14] The higher the scores, the better is the QOL.[8]

MQOL is multidimensional, includes four scales: physical (items 1-4), psychological (items 5-8), existential which include outlook in life and meaningful existence (items 9-14) and support domains (item 15 and 16).[1,8,16]

The scale items are:

1.	Physical symptom 1....	tremendous problem/no problem
2.	Physical symptom 2	
3.	Physical symptom 3	
4.	Physically I felt	terrible-well
5.	I was depressed	always-never
6.	I was nervous or worried.....	extremely-not at all
7.	How much of the time do I feel sad?	always-never
8.	When I think about the future, I'm..	consistently terrified-not afraid
9.	My personal existence...	meaningless and without purpose-meaningful and purposeful
10.	In achieving life goals, I have.....	made no progress whatsoever-progressed to complete fulfillment

11. My life to this point has been....	completely worthless-very worthwhile
12. I have....	no control- complete control over my life
13. I feel good about myself as a person...	completely disagree- agree
14. Everyday seems to be...	A burden-a gift
15. The world is	an impersonal, unfeeling place-caring and responsive to my needs
16. I feel supported...	not at al-completely

It is reported that there is no ideal QOL instrument for all stages, place of care, nature of disease and culture. According to Cohen, et al, MQOL is relevant to all phases of the disease trajectory for patients with a life-threatening illness.[1,15] It has been widely used in cancer and HIV/AIDS and proven as a suitable QOL instrument in Asia countries. Psychometric testing of the translated MQOL Taiwan Version done by Wy, H et al demonstrates the acceptability, reliability and validity of the instrument.[12] Another cross cultural validation of MQOL questionnaire has been shown in a study conducted in Hongkong by RS Lo, et al. The study shows that the domains covered in this instrument are all relevant and applicable.[13]

The questionnaire differs from most other QOL instruments in these points: existential domain is concerned, physical symptom is considered important but not predominant, therefore not excessively explored and positive contributions to QOL are measured.[1]

The acceptability, validity, reliability and internal consistency of this instrument have been demonstrated through various studies.[1,15,10] Compared to other QOL instruments, such as EORTC, the number of questions (16) is more acceptable. The time needed to complete MQOL instrument (10-30 minutes) is tolerable to palliative care patients.[15]

The above facts about MQOL show that this instrument fulfills the criteria for a QOL self assessment as cited by Yates: [9]

- Multidimensional
- Brief
- Consistently measures what it is purported (reliability and validity)
- Sensitively used in clinical changes
- Clearly and significantly contribute to patient care
- Highly acceptable to patients
- Easily interpreted by clinicians and those measuring QOL

Conclusion

Measuring QOL is problematic in palliative care practice. First, the patient's condition may result in the difficulty in assessing and interpreting the data. Second, the instrument used may not include domains which are relevant to the patients, not acceptable, valid, reliable or consistent. MQOL version 1996 is suggested for patients in palliative stage as it fulfills the criteria for QOL self instrument and has been proven relevant and applicable in Asia countries.

Reference

1. Annels, M and Koch, T. 2001, "The Real Stuff: Implications for Nursing of Assessing and Measuring a Terminally Ill Person's QOL" in Journal of Clinical Nursing, 10: 806-812
2. Brady, M et al. 1999: "A case for Including Spirituality in Quality of Life Measurement in Oncology", in Psycho-Oncology 8: 417-428
3. Clinch, JJ et al. 1999, "Quality of Life Assessment in Palliative Care", in Oxford Textbook of Palliative Medicine, 2nd ed, pp 83-93
4. Cohen, S.R et al, 1995, "The McGill Quality of Life Questionnaire: a measure of QOL appropriate for people with advanced disease: A preliminary study of validity and acceptability" in Palliative Medicine : 9:2007-219
5. Cohen, S.R, 2002, " What determines the QOL of terminally ill cancer patients from their own perspective", in Journal of Palliative Care 181/2002: 48-56
6. Cohen, S.R et al. 1997, 'Validity of the QOL in Palliative Care Setting: a Multi-centre Canadian Study demonstrating the importance of the existential domain" in Palliative Medicine Jan; 11(1): 3-20
7. Cohen, S.R et al. 1996, 'McGill QOL Questionnaire '
8. Coutens, A. 2001, 'Instruments to asses QOL of Palliative Care' in Evidence –Based Palliative Care, A Cross the Life Span, Blackwell Science Ltd, pp 103-115
9. Hean J and Hig Ginson I.J, 2001, " Outcome measure in palliative care for advanced cancer patients: a review", in Researching Palliative Care, ed. D. Field et al, Open University Press, pp. 127-140
10. Jochan, H.R. et al, 2006, "Quality of Life in Palliative Care Cancer Patients: a Literature Review", in Journal of Clinical Nursing, 15:1188-1195
11. Kaasa S and Loge, J.H. 2002, " Quality of Life assessment in Palliative Care" in The Lancet Oncology, vol 3, March 2002, 175-181
12. Kaasa S and Loge, J.H. 2003, " Quality of Life in Palliative Care: Principle and Practice" in Palliative Medicine: 17:11-20
13. Lo, R.S, et al. 2001, " Cross Culture Validation of the McGill QOL in Hong Kong Culture" in Palliative Medicine, Sep 15 (5) 387-397
14. Wy, H. et al, 2003, " Psychometric testing of the translated McGill Questionnaire: Taiwan version, in *Forma* Medical Association, Feb 102 (2): 97-104
15. Yates, P: Can we assess QOL, in study guide