Review Article

A Guide to Selecting a Measurement Tool for Quality of Life Assessment

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Abstract
Modern approaches to patient treatment and personalized medicine increasingly recognize the importance of the patient's quality of life outcome. The art of assessing and using quality of life information in routine practice remains a challenge and poses a stumbling block for clinicians. This critical review of the literature identifies useful measures to minimize those challenges and guide nurses and researchers in selecting the correct tool for measuring quality of life in their clinical setting.

Introduction
Quality of Life (QoL) is a multidimensional concept with a great deal of diversity in terms of interpretation and understanding. Having no cultural boundaries, the QoL of an individual is influenced by intrinsic and extrinsic factors such as our hopes, expectations, disappointments and joys; social circumstances; illness; ability to function; interaction with other people and general wellbeing the list is infinite. These influences are so unique and fluid within each person, that the concept may be described as 'amorphous or 'loose'[1,2].

Defining QoL
Deconstructed to its most rudimentary, quality is defined in the Oxford English dictionary as 'The standard of something as measured against other things of a similar kind", while life is defined as 'The existence of an individual human being or animal'. Application of this definition in its most elementary context, would suggest that QoL must be measured against a predefined standard of QoL of 'other' individual's. One of the main controversies of the QoL discussion is not that standards should exist but rather who sets those standards- should they come from within the individual or are external values of others imposed?

The World Health Organisation places the individual firmly at the heart of this controversy and gives the individual the ownership of those standards by defining QoL as "*An individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, and their relationships to salient features of their environment*'[3].

Typically, QoL assessment tools measures four dimensions in QoL functional, psychological, physical and social status. The dynamic and individual nature of QoL is difficult to capture when using (nomethic) questionnaires based on grouped data, in which the questions asked, the response format provided, and the relative weights applied to the answers, have all been predetermined[4,5]. While such measures, which are generally referred to as Health Related QoL (HRQoL) measures, provide important information regarding health status, their promulgation as measures of QoL is more questionable [6-8]. Many would postulate that these attributes alone are not entirely synonymous with QoL while Hunt suggests that HRQoL isolates the person from the social and material conditions in which they exist[7,9,10].

Moulton points out that the ideal balance has yet to be struck in clinical practice[11]. The individual's own view of their present reality hopes and expectations can only be described by the individual[4,7, 12-14]. Calman[15] defined QoL in cancer patients as the difference, or the gap, at a particular point in time, between the hopes and expectations of the individual and that individual's present experiences. While subjective QoL measures are increasingly replacing objective measures, the content of such measures is still largely predetermined by the investigator. It has been proposed that a valid QoL measure for patients should permit one to assess QoL from the unique perspective of the individual without imposing a predetermined external value system.

Questionnaires measuring QoL are by necessity, predetermined, and may be missing out on issues of relevance to the individual[7]. Individual QoL is phenomenological in nature and as LeVasseur et al. suggest an individual approach acknowledges the central role the person plays in the observation[16]. Smout et al, study supports this premise, demonstrating an inverse correlation between family member's evaluation of the patients' QoL and the actual patients own assessment of their own QoL[17]. As seen in a number of studies, life domains such as leisure, family and work are predominantly elicited as significant more often by patients than by a healthy population[16,18-20].

The Schedule for the Evaluation of Individual Quality of Life (SEIQoL) is a phenonomenological approach to measurement of QoL, in which the terms of reference are determined by the individual [21]. The SEIQoL was developed based on the premise that QoL is individual in nature and that a person judges it on the basis of his or her evaluation on how they are doing in a number of salient life areas[18,19,21]. The definition being: '*QoL is as the patient says it is*'. The measure was designed to answer three questions about an individual's QoL: (i) what areas of life are important to the respondent (cues) elicited by means of a structured interview (ii) how the individual is currently doing in each of these areas (levels) measured on a visual analogue scale; (iii) what is the relative importance of each of these areas (weights) by using a technique called judgement analysis. Judgement analysis is a research method often used in studies of judgement and decision making and externalises the way a person makes a judgement or decision. Its goal is to quantify the relationship between the judgement and the information used to make that judgement. Using the SEIQoL measurement instrument, the individual needs to be able, to think abstractly and form their own judgement. It is therefore not a suitable assessment tool for individuals with cognitive impairment.

Measuring QoL
The miscellany of descriptions and definitions of QoL has led to many approaches in its measurement and consequently the creation of a vast number of tools to measure it. With the inordinate availability of QoL measurement instruments to choose from, the task of selecting the correct one for use in clinical practice presents a challenge for clinicians.The choice of measurement tool is often driven by, the user, his/her discipline and agenda. However, understanding the patient should be resolute within the selection process[1]. A "one size does not necessarily fit all approach" should be observed. It has been suggested that asking the following questions will help select the best tool to use when assessing QoL in the clinical setting; (a) Have existing tools already been used in the measurement of QoL in this setting? (b)What measurement constitutes importance changes in QoL?[22]. The purpose of the QoL assessment should be clear. Specific measurable objectives and outcome criteria should be defined from the outset using the SMART framework so that results of the assessment can be accurately measured[23].

Selection criteria for measurement tools
QoL measurement instruments, as with all health measurement instruments, must meet certain criteria that will add weight to the validity of the results. The criteria such as validity, appropriateness, acceptability, interpretability, reliability sensitivity serve as guidance when selecting any measurement tool and should be carefully considered before embarking on a project[22,24,25]. These properties are discussed within the context of QoL assessment to facilitate

clinicians when choosing a tool most suitable for application in their clinical setting.

Validity means that the tools measures what it purports to measure. The process of validation involves accumulating evidence to provide a sound scientific basis for the interpretation of test scores. Choosing the right tool for the right population is important. Validity and reliability of an instrument used in one population does not necessarily imply validity and reliability across all groups because as illness and health changes, objectives for assessment will differ [26]. It is therefore important to determine if the tool was previously validated within the population of interest. The different aspects of validity are explained in Table 1. The way questions are framed on a QoL tool may give rise to challenges in validity. For example, absence of an option to provide a negative response in a QoL tool may result in a false positive result.

Table 1

Types of validity	
Face Validity	• At face value, the instrument should measure QoL. What is being measured should not be unambiguous.
Content Validity	• The components of the scale/item should cover all aspects of the attributes to be measured. • The content of each variable should match the name which has been given to it. • Each item should fall into at least one of the objectives or content areas examined. If it does not, then the item is not relevant to the scale's objective, or the list of scale objectives is not comprehensive. • The number of items in each area should also reflect its importance to the attribute.
Criterion Validity	• This is divided into two types: a) Concurrent validity refers to the tools correlation with the outcome assessed. b) Predictive validity - asks whether the measure predicts future differences. • Using this tool the variable should be measured with accuracy. • The traditional definition of criterion validity is the correlation of a scale with a gold-standard.
Construct Validity	• The tool should offer construct validity. Construct validity is an ongoing process of learning more about the construct, making new predictions and then testing them. • Underlying psychological or sociological factors are referred to as hypothetical constructs. • A construct can be thought as a 'mini theory' to explain the relationships among various behaviors or attitudes.

Appropriateness refers to the extent to which instruments content is appropriate to the application. Careful consideration should be given to the purpose of the QoL assessment with reference to the nature of the patient group, the area of health and the content of possible instruments. The population should be willingly to disclose information regarding their QoL information and the questions should be appropriate to elicit a response.The properties of the

instrument should be sufficiently robust to answer the question in a way that can actively discriminate and measure the influence of covariables and provide results that are exact and precise for the scientific community to hold value[27]. Clinicians may find some questionnaires bear little relevance on the QoL of their population and thus the application of such tools will bear little value[9].To this end it is suggested when evaluating QoL research studies, the description of the tool and the scientific criteria for selecting the specific instrument should be clearly described along with the rationale for selecting it, instructions on how to measure the scores and the interpretation of the scores or results[9].

Acceptability is the extent to which an instrument is acceptable to its users- i.e., both the administrator and the respondent. Indicators of acceptability include administration time, response rates, and levels of missing data. There are several factors that can influence acceptability such as the mode of administration, questionnaire design, and the health status of respondents. The clinician must know how to use the tool, understand its output and agree to use it. Change of practice is sometimes a challenge and needs to be handled well to succeed. Implementing change in practice needs to be applied under a framework of evidenced based practice[28]. To facilitate the process and encourage change of attitude and use of the tool, information and education must be provided to the clinical team regarding the change itself, *'the tool'*, how to use the tool and how to use the QoL information derived from this tool. It may give rise to QoL issues that the clinician must be prepared to address or manage. The frequency of QoL measurement must also be acceptable. There is no agreed standard for frequency for QoL assessment. As there are many social, personal and environmental determinants of QoL that reach beyond the influence of any one intervention, to measure change, it is important to capture a base line measurement and then measure longitudinally over the course of time. This may pose a challenge for the administrator in terms of resources and also in recognizing a time period that will be sufficient for change in QoL to occur and for it to be observed[29]. Assessment designed to mirror the way decisions are made in clinical practice, *i.e.* over the course of time will influence the acceptability. QoL assessment at one single time point does not reflect QoL trajectory of the patient but captures the measurement at that point in time.

The format of patient-reported instruments can also influence acceptability for the respondent or patient. It should not be difficult for the patient to understand and complete. General features of layout, appearance, and legibility are thought to be important influences on acceptability. It should be sensible in its use for purpose[30]. The language should be sensible, plain and understandable so that the concept can be accepted. The questions should be specific and there should be a defined period in which the respondent can answer the questions. Introductory questions should be easy to answer as this will instill confidence and encourage completion. Generating unwanted questions on QoL questionnaires leads to unwanted *'noise'* and may result in failing to address the important questions or may result in getting a reduced response to the important questions[25].

Most QoL tools are created in the English language. Translating a tool into another language may be potentially unsuccessful because of incongruent colloquial interpretation due to cultural differences. A set of standardized guidelines will assist with the cross-cultural adaptation of QoL Questionnaires [31]. The guidelines recommend several translations from several qualified translators should first be

obtained followed by the production of back translations (translate back from new language to original source for comparison). An independent committee should then review the revised document and a structured approach should be employed to resolve discrepancies. The final questionnaire should be pre-tested before routine use.

Interpretability concerns the degree to which one can assign meaning to the results. The instrument should produce results that can be easily interpreted, are meaningful to the research question, measurable and accurate. In addition to this, the process for interpreting and translating the results/ scores into useable information that can be easily understood must be an achievable, non-arduous task. This is a common challenge with QoL instruments particularly with paper-based questionnaires that are not conducive to real time access of results. Isolating the influence of co-variables on QoL is a challenge when interpreting results. In many cases, there is an attempt to blame the study design or the hypothesis for the negative outcome whereas, in fact, several co variables might have contributed to the outcome[28].

Reliability concerns how well the instrument will provide consistent results. There should be internal consistency meaning the target that is being measured, is being done so consistently. Reliability also assesses the extent to which an instrument is free from error. The results should be reproducible –meaning that the instrument should measure the same thing repeatedly in the same population. To ensure consistency in the reliability of the instrument, comparing studies using different study designs- for example comparing a retrospective study versus prospective study would not be recommended. The instrument must also reliably reflect the patient's experience[32].

Sensitivity or Responsiveness of a QoL measurement tool is concerned with the measurement of significant changes in QoL and the ability of the instrument to correctly detect a meaningful change or clinically important change. This is perhaps the most important criterion for the selection of a measurement tool to evaluate patient outcomes. While some QoL studies informs on the usefulness of QoL information in the clinical setting, many do not demonstrate the actual mechanism of action or explain the reasons for the outcome. Caution should be given to negative results of QoL information and patient reported outcome as there may be an inaccurate assumption that the QoL intervention itself is ineffective[33]. Inadequate sensitivity may lead to a 'false negative' in which the intervention truly improves how the patient feels but the measure fails to detect that improvement. It is important to determine predisposing factors which might influence the sensitivity of the measurement tool such as a ceiling effect where, for example, a subscale indicates the complete absence of dysfunction and therefore on cannot show any further improvement. Sensitivity might also be negatively influenced if the sample size is too small. A sensitivity value of 0.2 is indicative of modest sensitivity of a measurement tool[34]. QoL assessment tools also need to be 'culturally sensitive' to accurately detect changes amongst different cultural groups[26].

Response Shift: When an individual is faced with a crisis, events occur to enable him/her adapts and cope. Areas of life previously meaningful to an individual can shift through a process of *'adaptation'* and the individual's internal frame of reference appears to recalibrate. This, is commonly observed, in people who live with chronic illness, or whose clinical state cannot be improved[1]. This process of adaption known as 'intra subject construct dynamism' or

'response shift' which is described as a complex, multifaceted and dynamic reality of patient adaptation to illness[35]. The changes that occur can be described as(1) alpha change being true behavioral change, the person develops new coping skills and (2) beta change meaning recalibration, where the person, reassesses the weight of importance (3) gamma change which means redefining the values which gives it a difference[36].

A key challenge associated with measuring QoL is that the individual changes over time and as such the measurement instrument must capture those changes and discriminate between the true longitudinal effects of treatment over time[25]. Discriminate measurement instruments measures whether a patient has good QoL and 'evaluative measurement instruments' captures the actual value of the improvement of a patient's QoL. It is important to remember the response shift phenomena, especially as may serve to attenuate or to exaggerate estimates of treatment effects as patients adapt to treatment toxicities or disease progression over time[36]. Keeping in mind the criteria/standards required for measurement tools as outlined above, it is suggested that there are two fundamental groups of QoL researchers those who agree on the functional components of questionnaires and use of instruments tailored to measure the area of interest to reflect the researchers' preoccupation and those researchers who do not agree on any one customary measurement tool nor that there a decisive factor upon which QoL can be measured as it is conceptual in nature and not definitive or static in behavior[9]. The latter profess that there is no mean or average measurement as each individual present with an innumerable factor which influence QoL, those factors being experienced only by that individual and influenced by both intrinsic conditions such as emotional stability, moods, feelings, perceptions and extrinsic factors such as health and supports available to him[21,37-39]. In line with this discipline of thought, tools for measuring QoL can be further subdivided into 'generic' or 'disease specific' and 'Individual' tools. A combined approach may be valuable.

Types of QoL Measurement Tools
Generic QoL measures
These tools are designed for use with any group of illness or any population to assess the extent to which an intervention affected the patient's overall life and they have a wide application across patients with different characteristics. Generic measures are necessary to compare outcomes across different populations and interventions, particularly for cost-effectiveness studies. An example of a generic QoL tool is the Short Form-36 (SF-36). This was developed in the United States and covers eight dimensions:

• Physical functioning • Social functioning • Role limitations due to physical problems • Role limitations due to emotional problems • Mental health • Energy/vitality • Pain • General health perception. The SF-36 is rapidly becoming the generic health status measure of choice. It is frequently recommended as the generic core in disease specific questionnaires, but it is not necessarily the *'gold standard'* appropriate to all studies in all instances. A 12-item version (SF-12) has also been developed, with initial results suggesting SF-12 summary scores to be very similar to the longer SF-36 summary scores.

Health RelatedQoL Measures
Many healthcare clinicians concentrate on a sub-component of QoL known as Health Related QoL (HRQoL) that was first used as an index medicus in 1977[1]. HRQoL questionnaires focus on effects attributable to specific disease, diagnosis or population or group of patients[24]. There are theoretical advantages to this approach. Specific instruments are more responsive than generic tools and completion of the QoL questionnaire is facilitated by only including dimensions relevant to the disease of interest[40]. These instruments can provide new insights into relationships between QoL and risk factors and can lend itself significantly to determining the burden of disability of a specific disease and aide in public policy planning. Results shouldn't be compared with those from other disease groups and specific dimensions or domains of importance to the patients QoL may not be included in disease specific measurement tools.

HRQoL tools may be further divided into disease specific measures an example of this is the cancer-specific health related tool , the 'EORTC QLQ C-30'.This is a 30-item questionnaire developed by the European Organisation for Research and Treatment of Cancer [41]. The core questionnaire incorporates a range of physical, emotional and social health issues relevant to a broad spectrum of cancer patients, irrespective of specific site of their disease or type of cancer. This core questionnaire is then supplemented by diagnosis-specific and/or treatment-specific questionnaires.

Individual QoL Measures
It is postulated that the functional, psychological, physical and social status attributes alone are not entirely synonymous with QoLand thus may isolate the person from the social and material conditions in which they exist. Individual QoL is not just about health but rather is all encompassing of the individual whose QoL satisfaction is both positively and negatively influenced by the perception of aspects of life that are important to him[1,4,7,10, 42-45].

The Schedule for the Evaluation of Individual Quality of Life- Direct Weighting (SEIQOL -DW) instrument is a validated tool, designed to measure QoL from the unique perspective of the individual without imposing a predetermined external value system[1,4,42,46].The main feature of this tool is that the individual judges the overall quality of the discrete domains of life which they consider important and influenced by a variety of factors, including experience and expectations. Each important aspect of their life is measured in terms of its relationship to worst and best possible states. The SEIQoL DW is simple and user-friendly tool developed based on the same concept of longer versioned SEIQoL tool and takes 15 minutes on average to complete[7].

Conclusion
QoL was traditionally an area of interest in palliative medicine perceived to be associated with facilitating patients during their transition from life to death. Modern approaches to patient treatment increasingly recognize the importance of patient reported outcomes and the need to incorporate the views of patients in treatment planning. While improving patient QoL is now an important goal in healthcare and although widely accepted that it should be considered as a primary endpoint of treatment both in clinical practice and clinical trials, translation into the acute medical setting has not been yet prioritised to any great extent. The important question of the response shift of QoL or the dynamism of the individual's view of their QoL over time needs to be incorporated into clinical trials, otherwise outcome measurements may exaggerate or undervalue *'actual'* QoL. The 'value' of using QoL outcome information as an actual *'Clinical Tool'*, needs to be addressed.

The art of assessing QoL is developmental. No single measure satisfies the multidimensional and subjective components of QoL and with the growing number of instruments available for the measurement of QoL, clinicians must be careful to select those outcome tools that are best suited to detect the primary outcomes of interest for a specific population. Selecting the correct tool will better inform the clinician about the patient on which clinical decisions can be based to ultimately improve the patients overall clinical outcome. Temel et al [47], suggests that early palliative care integration, accounts for improvements in both the outcomes of survival and QoL for patients with metastatic non–small-cell lung cancer[47].

It should be possible to measure HRQoL and individualised QoL in studies where both outcomes are very relevant, for example, the palliative oncology setting. The incorporation of assessment of *'response shift'* is more challenging as it requires an understanding of how as *'humans'* we can recalibrate in areas that matter to our QoL overtime, especially when facing a terminal illness.

The practice of using QoL information as a clinical tool in the acute care setting could have far reaching implications, not only for the patient in terms of improvement in health and wellbeing but it may go toward lessening the burden of disease on the state and could be used by acute health care institutions as a tangible measure of quality in health. Patient reported individual SEIQoL-DW information, graphically presented for ease of interpretability by clinicians could benefit the patient. This approach could be used by, acute health care institutions as a tangible measure of quality in health to complement traditional outcome measures of survival, tumour response and HRQoL measures. It may offer a more comprehensive, tailored and personalised approach in evaluating the relative risks and benefits associated with treatments in harmony with patient preferences.

Acknowledgement

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