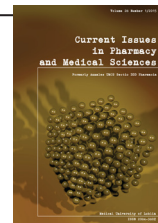


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## Is the vignette method used to assess quality of life in practice?

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### ABSTRACT

**Purpose.** To define how extensive is the use of the vignettes method for quality of life assessment.

**Methods.** An internet search of different databases was performed to identify and enumerate the publications involving studies in which the vignettes method is employed in relation to quality of life assessment (QoL). PubMed-Medline and Cochrane were scrutinized for publications based on the same search criteria.

**Results.** Our search found that 6 Cochrane and 105 Medline publications, as well as 28 articles were published between 2011-2014. However, only 7 match the objective of the search.

**Conclusion.** The rating of vignettes is a promising additional technique to measure changes in QoL and utilities, however, it is not very often employed by the researchers. It can be considered for use as supplementary method to standard QoL measurement methods.

### INTRODUCTION

Quality of Life (QoL) is a term used in medical and social science. It is a very wide concept related to almost all significant spheres of life [8]. L. Nordenfelt [11] identifies quality of life with the cognition and emotional subjective perceptions of the world. All individuals experience emotions. If their emotions can be described as positive, then the quality of their life can be estimated as being high, regardless of the fact of being sick or not. J.M. Raeburn and I. Rootman suggest a similar understanding of the concept of quality of life. J.M. Raeburn and I. Rootman argue that the more the individual feels satisfied, the higher is their quality of life [15].

Overall, quality of life, as already mentioned, is a broad concept describing an individual's general well-being. This is influenced by numerous aspects of life, both health and non-health related. Quality of life, being an important factor for all humans, should also be considered and assessed during the treatment process alongside different disease areas. It is especially important to measure health-related

quality of life when investigating chronic diseases, when improvements in function are expected, or when it is aimed to demonstrate the treatment impact on long-term quality of life considering safety aspects of the treatment. Of note, one of the more efficient methods of evaluating the quality of life of a patient is a direct interview. Health-related quality of life instruments can measure health-related quality of life as a clinical endpoint or can be used to generate data that can be incorporated into an economic evaluation. QoL is incorporated into the economic evaluation through the Quality-Adjusted Life Years (QALYs). What is really included in the QALY is the utility of the health state. Those utilities can be calculated using different methods such as the Standard Gamble (SG), Time Trade Off (TTO) and the Visual Analog Scale (VAS), or derived from different QoL questionnaires like e.g. EQ-5D or the Health Utility Index (HUI). The methods to calculate utilities can, however, create some difficulties for patients. The easy one to comprehend is the VAS. This is single line, with verbal and numerical descriptions at each end. The ends represent usually 'death' and 'perfect health' as reference states. Respondents are asked to rank the health states in order of preference, and then to rate the desirability of each, by marking a point on the line on

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or between the two endpoints, so that the intervals between states correspond to the strength of their preference.

The SG and TTO methods are more complex and require good cooperation with the respondents. In using the SG technique, the probabilities in the gamble are varied until the respondent is indifferent between the gamble, while the TTO technique can be used to establish the utility of a described health state by asking a respondent to choose between two different options, for example: living on dialysis for 30 years or living in perfect health for a shorter period of time. In employing this technique, what varies is the length of life in perfect health until the respondent is indifferent between the two options.

The QoL questionnaires used to measure health related quality of life can be general or disease specific. Those general can be used for utilities calculations. Those which are specific for the one disease area, are more sensitive, but still do not capture the very small changes.

Despite the great variety of available QoL questionnaires, there are areas for capturing information, often that of a sensitive nature, using other tools, such as vignettes. In psychology and sociology, a vignette describes a hypothetical situation to which research participants respond and reveal their perceptions, values, social norms or impressions of that which is presented within the vignette events. For health related research purposes, vignettes can be also used as a method to describe health states in a simple and understandable way to patients.

A clinical vignette is applied to a single patient, and the information given during an interview can explain and elaborate upon why the patient achieves high scores in the study of quality of life or why the result is disproportionately low. The objective of our search was to define, if in real life, vignettes are used for quality of life or utilities assessment, and if yes, how extensive their use is.

## MATERIAL AND METHODS

The analysis we performed was based on a literature search using the Internet. Herein, the Medline-PubMed and Cochrane Library databases were reviewed. The initial search was focused on the term “quality of life”. A second search was restricted to ‘quality of life AND the use of vignettes in the performed studies’. The search strategy was based on the terms: “vignette” [All Fields] AND “quality of life” [All Fields]. Upon reviewing all obtained publications from the performed search, we analyzed in detail the publications from the period between the years 2011-2014. The search timeframe was set up for the last 4 years due to the rapid development of the diverse areas where the vignettes approach can be of use. The methodology is presented in the diagram.

The identified abstracts were reviewed to ascertain whether they meet the criteria of quality of life studies using vignettes. Those abstracts fulfilling the criteria of this project were selected and full publications reviewed for objectives, methodology and outcomes of the studies.

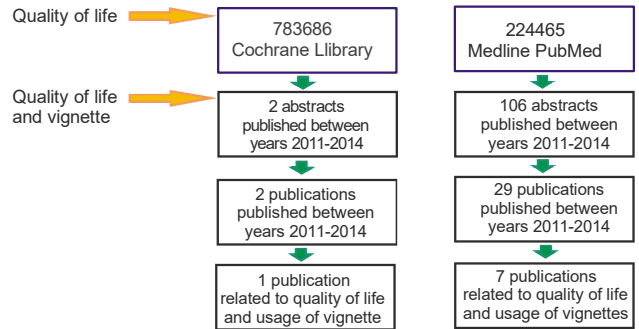


Diagram 1. Search strategies in the library databases

## RESULTS

The complete list of the analyzed publications is presented in the Appendix.

In the Cochrane Library, there were 6 results from 783686 records at the time of the last search (15 April 2014). Only 2 papers were published between the years 2011-2014, and only one publication, by Xie, Oremus and Gaebel, was about health-related quality-of-life and the vignettes method. Therein, the authors performed a measurement in relation to Alzheimer’s disease (AD), using the general public and they used vignettes when interviewing study participants to describe mild, moderate, or severe AD. The participants answered the EQ-5D-5L and Quality-of-life-Alzheimer’s Disease (QoL-AD), while imagining living in the health state described in their assigned vignette. Moreover, they answered the EQ-5D-5L based on their health state at the time of the interview [22].

The other identified publication was not focused on QoL. The video vignettes illustrating staff-resident interactions were used for an assessment of staff nursing choice offered to long-stay nursing home residents [17].

The last search on Medline PubMed was done on 08 July 2014, and we identified a total of 224465 publications referring to quality of life. With the restricted search to both quality of life and vignettes, we identified 106 abstracts. Altogether, there were 29 publications corresponding to the selected time period.

After taking into account the assumed search criteria, analyzing titles and abstracts of scientific reports, we rejected unsuitable publications in terms of topic and repeated publications.

After exclusion of the reports which did not meet the basic criteria for inclusion in the analysis, there were 6 publications found related to quality of life and usage of vignettes during the analyzed period of time.

The vignettes were used by the authors to assess quality of life and/or utilities in different disease areas and health states.

The search revealed that Shingler S.L. et al. developed eight health state vignettes, and in a sample of 100 members of the UK general public, assessed utility values using the time trade-off procedure for soft tissue carcinoma [20]. Moreover, Frederix G.W. et al. assessed utility values in lay-people and productivity loss for women with breast cancer in Sweden and the Netherlands. They used validated health state vignettes translated into Dutch and Swedish describing

progressive disease, stable disease, and 7 grade 3/4 adverse events [6].

Vignettes have also been used in a study assessing physicians' attitudes regarding the impact of ADHD on health-related quality of life for prescribing psycho-stimulants in children. For such purpose, the involved physicians used a preference-based assessment of HRQL (Standard Gamble method) to rate four vignettes describing ADHD health states of varying severity [19].

Another study, aiming at utilities assessment in relation to schizophrenia treatment, was done with the TTO method and the use of vignettes. Therein, the authors estimated by way of four developed vignettes, the utility values for alternative treatment intervals for long acting antipsychotic intramuscular injections for the treatment of schizophrenia. The vignettes were developed using the published literature and an iterative consultation process with expert clinicians and patient representative groups. One vignette was for relapsed/untreated schizophrenia, while three others presented a standardized picture of well-managed schizophrenia with variations in the intervals between injections. The utility values for the vignettes were obtained by a standardized time trade off (TTO) method [12].

In one more study, Swinburn P et al., by using health states vignettes, described the burdens associated with receiving therapy for advanced neuroendocrine tumors elicited utilities. These authors developed the vignettes based on literature review data and direct interviews with clinicians and patients in order to describe health states. The burden related to stable and progressive disease and also some toxicities were described in those states. These were then validated with a TTO method, for utility values. In their study, the authors concluded that although vignette studies have been criticized for the difficulty in establishing their validity, the collection of health utilities in rare populations is challenging. They found that advanced NETs is associated with a considerable HRQoL burden, and the utility values obtained, could be of use in future economic evaluation processes [21].

Another use of vignettes for eliciting utilities is the publication by Farshad M et al, who due to limited available data related to correlation between the scores and quality of life, and no available information about the impact of scores on utilities, aimed towards determining utility values in patients with anterior cruciate ligament injuries. The authors' objective was to compare the most commonly used scores for evaluating patients with anterior cruciate ligament (ACL) injuries, and to establish corresponding utility values. Based on different levels of activities after rupture of the anterior cruciate ligament, four vignettes were defined. The aim was to simulate typical situations seen in daily practice. A questionnaire, including the Health Utility Index (HUI) for utility values, the IKDC subjective score, as well as the Lysholm and the Tegner score, was used by surgeons and patients proxies of all the patients who fitted into the hypothetical vignettes. The authors showed that the utility value as an indicator for quality of life, increased with the level of activity. Despite the observed correlations in their opinion a systematic inclusion of a measurement instrument for utility values in future clinical studies is needed [5].

## DISCUSSION

Objective conditions related to health, are not unambiguous indicators of the sense of quality of life [4]. Indeed, medical personnel often encountered cases where patients rated the quality of their lives significantly higher than do healthy people. It seems obvious that every individual reacts differently to emerging crises in their life, and every disease can be treated in terms of a life crisis. The way of answering a vignette style question allows the performance of a profound diagnosis and can be a source of additional findings as a subjective self-evaluation of a patient's quality of life.

Vignettes are used in different types of research, however, this comes about not very often, especially taking into consideration that, in fact, this is not a new concept at all. In 1998, for example, B.R. Ferrell and M. McCaffery prepared a survey using vignettes focused on pain. The vignette, was the method used in their case study to obtain information about pain assessment, medication choices, and areas of knowledge and belief that influence nurses' choices. In their study, these authors presented two different hypothetical patients illustrating one concept in pain treatment. The same set of questions was addressed to nurses, asking for their assessment of patients' pain, their decision regarding medication dose to be administered and their identified concerns that influenced the responses to prior questions [2].

We have also observed that the vignettes have been employed not only to assess QoL or utilities, but also in uncertain situations in relation to quality of life. An example could be the paper by Ida J. Korfage et al. published in 2007, who used the rating of vignettes relating to the side effects of prostate cancer treatment (urinary, bowel and erectile dysfunction) [9]. In their work, the response shift in men diagnosed with prostate cancer was assessed. Therein, it was discovered that this response shift can be positive as adaptation to a new situation (the change in their health status). This different response can interfere with the standard QoL tests results. That is why the authors decided to use a new method utilizing vignettes to assess the response shift in the studied group of patients. The term 'response shift' refers to a change in the meaning of QoL over time [9], and can result from a change in one's internal standards of measurement (i.e. recalibration), a change in the importance attributed to the domains constituting QoL (i.e. change in values or re-prioritization), or a change in the definition of the concept of QoL (i.e. reconceptualization) [14,18].

Another publication described the use of a clinical vignette featuring the case of a comatose patient suffering from post-anoxic brain injury. In this work, responding intensivists participated in a study where a questionnaire and a semi-structured interview were used. Respondents were asked to present and discuss their perceived prognosis and expected outcome for the patient described in the vignette in the first part of the study. Therein, the questions to answer were: *What is the prognosis and outcome for this patient? What is the projected quality of life for this patient? What physical, mental, and social deficits is the patient likely to experience if treatment succeeds?* The second part consisted of an interview exploring four sets of fundamental factors



that can influence physician decision-making: professional experience; personal background; patient characteristics; and contextual factors [7].

In an additional study, vignettes derived from the Cooperative World Organization of National Colleges, Academies, and Academic Associations of Family Physicians, COOP/WONCA were used to assess the change in perception of health as measured by M. Gine-Garriga et al. [7].

In yet one more study, A.A. Quartin et al. analyzed the influence of critical illness on the physicians' prognoses. Their research was based on a web survey describing two case vignettes; one was with cardiomyopathy as the underlying disease, and the other one with lung cancer. Randomly assigned respondents were presented with either encountered septic shock or an uneventful clinic visit. The aim of the work was to assess the severity of the underlying disease and to predict survival time and QoL, while ignoring the presented context [13].

Another mentioned use for vignettes is when assessing utilities. J.L. Bosch et al., in 1998, published the results of a study where they used a single binary-gamble question per health state per respondent to obtain societal preferences for the health states of intermittent claudication and major amputation, and to compare these with Health Utilities Indices obtained from patients, so as to test the feasibility of this method, and to investigate whether the utility depends on the presentation of a vignette as generic vs disease-specific. Respondents had to answer questions for each of the health states. The health states were alternatively described by generic and disease-specific vignettes in two subsamples [3].

In an Australian national survey of mental health literacy, six vignettes (depression, depression with suicidal thoughts, early schizophrenia, chronic schizophrenia, social phobia or post-traumatic stress disorder) were used in order to investigate how participants would help the character in the vignette. This is an example of vignettes usage for assessment of people behaviours in the specifically defined situations [16].

Another survey to define preferences in relation to resuscitation activities was performed with the use of vignettes. In the survey, 8 vignettes were presented and the prognoses for survival and long-term outcome have been varied. The vignettes had outcome data for mortality and morbidity. In this work, respondents were asked about resuscitation in ethically difficult situations. They had to answer if resuscitation was in the patient's best interest and whether the physician would accede to requests for non-resuscitation [10].

Nicole Au and Paula K. Lorgelly showed that the vignettes can also be used with quality of life questionnaires such as the EQ-5D-5L. These authors developed a vignette for EQ-5D-5L and included it in an online survey. What is more, they performed in-depth interviews as follow-up with those who responded to the survey. In addition, they assessed the consistency of the response using qualitative analysis of the interview responses and quantitative coding of participants' thought processes. As a result, they concluded that the vignettes as an anchor to EQ-5D-5L are an option to be considered, however, their use is not for all patients, and if such usage is planned to be employed more widely,

the response consistency should be improved. Despite the identified consistency issues, the authors provided evidence of the effectiveness of using anchoring vignettes for the questionnaire. This, we feel is an important and significant piece of information for future work in addressing reporting heterogeneity within the EQ-5D-5L [1].

## CONCLUSIONS:

The rating of vignettes is a promising additional technique for measuring changes in QoL, however, this approach is not very often employed by the researchers. What information is available, demonstrates that vignettes can be considered for use as a supplementary method to standard QoL measurement methods.

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## APPENDIX

Cochrane Library	
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