EDUCATION & DEBATE

A new short form individual quality of life measure (SEIQoL-DW): application in a cohort of individuals with HIV/AIDS

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Quality of life is an increasingly important outcome measure in medicine and health care. Many measures of quality of life present patients with predetermined lists of questions that may or may not be relevant to the individual patient. This paper describes a brief measure, the SEIQoL-DW, which is derived from the schedule for evaluation of individual quality of life (SEIQoL). The measure allows respondents to nominate the areas of life which are most important, rate their level of functioning or satisfaction with each, and indicate the relative importance of each to their overall quality of life. Given its practicality and brevity, the measure should prove particularly useful in clinical situations where patient generated data on quality of life is important. This article describes the first clinical application of the measure, assessing the quality of life of a cohort of patients with HIV/AIDS managed in general practice.

Advances in diagnostic procedures, drugs, surgical techniques, and technology have rendered many acute conditions treatable, resulting in a shift in the focus of modern medicine to the management of chronic conditions. The management of chronic disease in general practice is a familiar responsibility. HIV/AIDS involves general practitioners in the management of minor illness, the referral of major illness, monitoring of disease progression, supervision of medication, support for carers, palliative care, psychological support, and many other roles. A common theme to these roles is the maintenance of quality of life.

Measuring the quality of life

The methodology used to evaluate quality of life has received considerable attention in the past decade.[1-4] Traditional questionnaires impose an external value system, and weighting of the component parts of the questionnaire is standardised and fixed and is generally derived from grouped data. Although these measures may be reliable, they may not be relevant to an individual's present life situation. Apparently similar behaviours do not have the same relevance or importance for all individuals. Furthermore, the relevance or importance of particular behaviours or events does not necessarily remain static for a given individual with the passage of time or over the course of an illness.[5] Thus, for valid measurement of quality of life a measure is needed that evaluates each individual on the basis of the areas of life that he or she considers to be most important, quantifies current functioning in each of these personally nominated life areas, and weights their relative importance for that individual at that particular time. A life area that is going badly for an individual but is of little importance to him or her clearly has less implication for that individual's quality of life than a life area that is going badly but is of great importance.

The schedule for the evaluation of individual quality of life (SEIQoL) was developed to assess quality of life from the individual's perspective.[5-7] It is an interview based instrument derived from a decision analysis technique known as judgment analysis.[8-10] The investigator can assess the level of functioning in, and relative importance of, those areas of life nominated by the respondent. The SEIQoL is a complex measure of a complex process and its use in routine clinical situations may prove impractical. We describe an abbreviated form of the measure, the SEIQoL-direct weighting (SEIQoL-DW),[11 12] which replaces the more cumbersome judgment analysis technique with a simpler procedure for measuring the relative importance (weights) to the respondent of nominated life areas.

The direct weighting instrument is a simple apparatus consisting of five interlocking, coloured laminated circular disks that can be rotated around a central point to form a type of pie chart. The laminated disks are mounted on a larger backing disk, which displays a scale from 0 to 100, and from which the relative size of each coloured segment can be read (fig 1). Each segment is labelled with a life area nominated by the respondent as being important to his or her overall quality of life. The respondent adjusts the disks until the size of each coloured segment corresponds to the relative importance of the life area represented by that segment. These segments may be adjusted and readjusted until respondents are satisfied that the
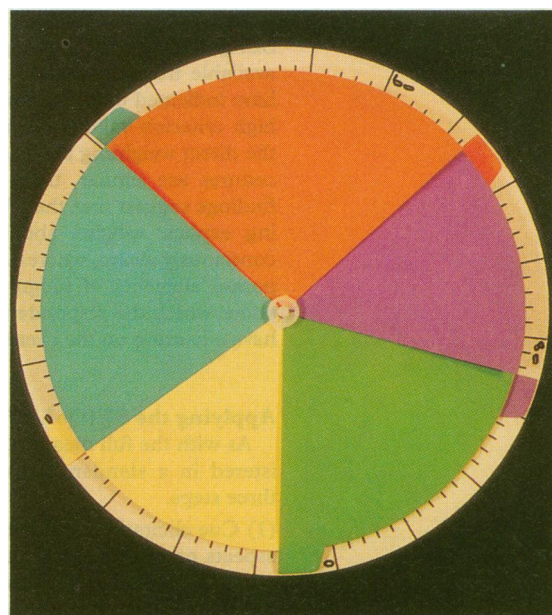

Fig 1—*The segments represent five areas of life nominated by the individual; the size of the segment can be adjusted to show the relative importance of each area for the individual's quality of life*
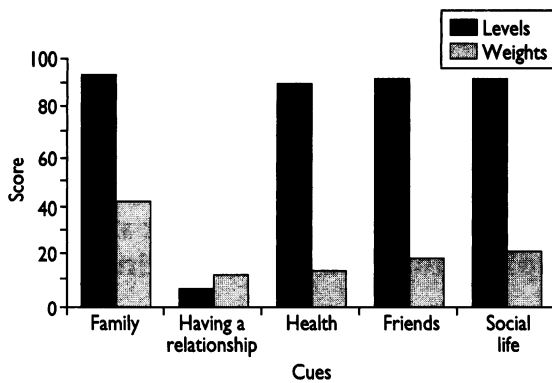
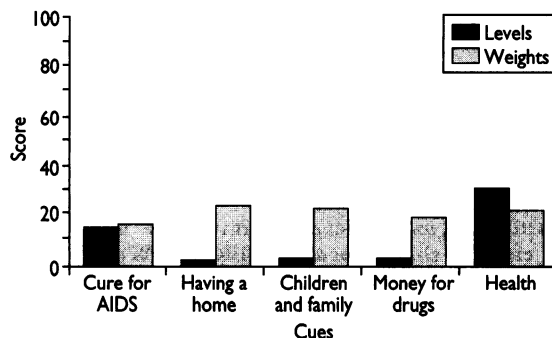**Fig 2**—*Quality of life profile of 31 year old man who formerly injected drugs*

Fig 3—*Quality of life profile of 27 year old woman, current injecting drug user*

proportion of the pie chart given to each life area accurately reflects the relative weights they attach to those life areas. If the respondent nominates fewer than five cues, the system allows for a corresponding number of segments to be manipulated. The weighting procedure is quick to administer, colourful, tactile, and easy to understand. The SEIQoL-DW was developed and validated against the full version of the SEIQoL and found to be a valid and reliable measure of explicit weighting policies for quality of life domains.[11]

PSYCHOMETRIC PROPERTIES

Detailed psychometric properties of the SEIQoL-DW will be reported elsewhere and are available from the authors. Studies in healthy subjects have indicated that the measure is reproducible and has high criterion validity. While the weights derived from the direct weighting and the full judgment analysis procedures are similar, there are some differences. The findings suggest that the SEIQoL-DW may be measuring explicit weights about which the respondent is consciously aware, whereas the full measure may incorporate elements of judgment which are implicit and about which the respondent is unaware but which may have a bearing on the overall judgment.[11]

Applying the SEIQoL-DW

As with the full measure, the SEIQoL-DW is administered in a standardised semistructured interview in three steps.

(1) Cue elicitation—"What are the five most important aspects of your life at the moment?" The individual is asked to name the five areas of life (cues) which are most important to the overall quality of his or her life. Respondents generally have no difficulty in identifying five important life areas, but if someone finds it difficult to nominate five areas, a standard list of prompts is used.

(2) Determining current status on each cue—"How would you rate yourself on each of these areas at the moment, on a scale from the worst possible to the best possible?" The respondent rates current status against a vertical visual analogue scale labelled at the upper extremity by "as good as could possibly be" and at the lower extremity by "as bad as could possibly be." These ratings are recorded in the form of a bar chart. The possible score range for each cue level is 0 to 100.

(3) Quantification of relative weighting of each cue—"How do the five areas compare in importance to each other?" This final step involves quantifying the relative contribution of each elicited cue to the judgment of overall quality of life using the direct weighting instrument described above. The total value of all five weights sums to 100.

The SEIQoL and SEIQoL-DW thus allow measurement of quality of life to be completely individualised. To present information as grouped data, for making group comparisons, it is possible to derive a single index from the data—the global quality of life score. This is calculated by multiplying the individual's current self rating on each cue by the corresponding cue weight and summing the products across the five cues. This global quality of life score can range from 0 to 100; it is a continuous measure which can be subjected to parametric statistical analyses.[6]

Clinical application of the SEIQoL-DW

The first clinical application of the SEIQoL-DW was in a cohort of patients with HIV/AIDS who were being managed in general practice. The case group consisted of 52 people known to be HIV positive, recruited primarily through two Dublin inner city general practices and receiving some form of ambulatory care. The comparison group consisted of healthy adults, matched for age and sex, drawn from the same neighbourhood.

Figures 2-4 show quality of life profiles for three of the seropositive patients. Figure 2 represents the quality of life profile of a 31 year old man who formerly injected drugs. He rated four of the five cues he nominated as very good, with the exception of the area "having a relationship." However, the weight he gave this last cue showed that he did not consider it important relative to the other cues; thus it did not impact greatly on his overall quality of life score, which was 82.08.

Figure 3 represents the quality of life profile of a 27 year old woman who injected drugs and was homeless at the time of interview. She had been involved in drug pushing in an effort to feed her own habit and consequently had been evicted from several homes by local residents. Her family had taken her children away from her and refused to see her or to let her have access to them. She indicated very poor status on all five nominated cues at the time of interview, in particular a home; children and family; and having money available to buy
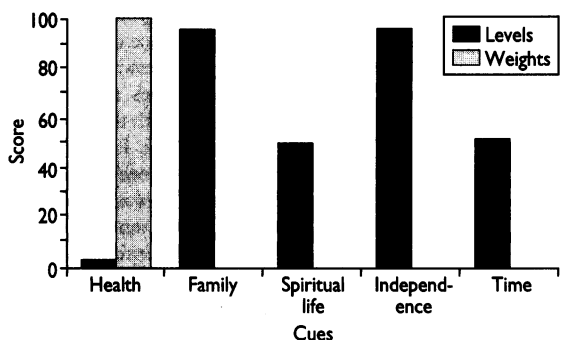

Fig 4—*Quality of life profile of 39 year old gay man, terminally ill*

Table 1—*Important life areas nominated by case and comparison groups*

Areas Important to cases (n = 52)		Areas Important to both groups	Areas Important to comparison group (n = 52)	
Area	% (No)		% (No)	Area
	71 (36)	Health	63 (33)	
	69 (35)	Family	88 (46)	
	59 (30)	Money, finances	46 (24)	
Drugs, access to physeptone	41 (21)			
	35 (18)	Children	25 (13)	
	33 (17)	Spouse or partner	42 (22)	
	31 (16)	Friends, social life	48 (25)	
Psychological factors: emotional wellbeing; sense of control; self acceptance; self esteem; feeling wanted	27 (14)		15 (18)	Psychological factors: being happy; concern for others; state of mind; way of life
	25 (13)	Independence, choice	8 (4)	
Issues relating to death: time left; issues to be faced; having things sorted out before I die; that a cure is found for the virus/AIDS	25 (13)			
	18 (9)	Living conditions	40 (21)	
Spirituality	16 (8)		6 (3)	Religion. God
	14 (7)	Sports, leisure	40 (21)	
	12 (6)	Work	62 (32)	
Having somewhere to live, a home	8 (4)			
Sex, lover, sexuality	8 (4)			
	4 (2)	Being able to get to work	4 (2)	
Miscellaneous	4 (2)			
			12 (6)	College, education

Table 2—*Important life areas nominated by gay and injecting drug users with HIV*

Areas Important to injecting drug users (n = 33)		Areas Important to both groups	Areas Important to gay patients (n = 17)	
Area	% (No)		% (No)	Area
	84 (27)	Family	35 (6)	
	12 (4)	Friends, social life	70 (12)	
	81 (26)	Health	53 (9)	
Drugs, access to physeptone	66 (21)			
	62 (20)	Money, finances	53 (9)	
Children	53 (17)			
	41 (13)	Spouse or partner	18 (3)	
	28 (9)	Issues relating to death: time left; telling my mother; having things sorted out before I die; that a cure is found for the virus/AIDS	24 (4)	
	22 (7)	Living conditions	12 (2)	
	19 (6)	Independence, choice	41 (7)	
Having somewhere to live, a home	12 (4)			
Psychological issues: keeping mind occupied; peace of mind	6 (2)		59 (10)	Psychological issues: controlling my destiny; emotional wellbeing; feeling wanted; self acceptance; self esteem; sense of control
			47 (8)	Spirituality
			35 (6)	Leisure pursuits
			29 (5)	Work
Being able to get work	6 (2)			
	3 (1)	Sex, lover, sexuality	18 (3)	
	3 (1)	Miscellaneous	6 (1)	

drugs. The weighting assigned to the five areas was approximately equivalent. The overall quality of life score was 9.96.

Figure 4 represents the quality of life profile of a 39 year old gay man who at the time of interview was considered to be terminally ill, although he subsequently lived for several months. He rated four of the cues he nominated as reasonably good to very good, but the area of "health" was rated "as bad as it could possibly be." When asked to weight his five nominated life areas relative to each other, he said that as long as his health was so poor, he could not give weighting to anything other than health, as his lack of good health meant that he was unable to enjoy any of the other important aspects of his life. The outcome of this weighting was an overall quality of life score of 3.

Table 1 compares the cues nominated by the case and comparison groups. There are many similarities in the areas identified: both groups nominated family and health most frequently. However, there are also important differences. Work was nominated by only 10% of the case group and 69% of the comparison group as an important life area; this may be explained in part by a higher employment rate among the comparison group, but it may also reflect differences in expectations or priorities in an HIV positive group, two thirds of whom were injecting drug users. Living conditions were nominated as important by both groups, but issues concerning homelessness were nominated by the case group only. Similarly, while spouse or partner was nominated as important by both groups, issues concerning sex and sexuality were nominated by the

Table 3—*Important life areas nominated by asymptomatic and symptomatic patients with HIV*

Areas important to asymptomatic group (n = 33)		Areas important to both groups	Areas important to symptomatic group (n = 19)	
Area	% (No)		% (No)	Area
	70 (23)	Health	72 (13)	
	61 (20)	Family	83 (15)	
	61 (20)	Money, finances	56 (10)	
	48 (16)	Drugs, access to physeptone	28 (5)	
	39 (13)	Spouse or partner	22 (4)	
	33 (11)	Children	39 (7)	
	33 (11)	Psychological issues: emotional wellbeing; self esteem; sense of control; self acceptance	17 (3)	
	30 (10)	Friends, social life	33 (6)	
	24 (8)	Issues relating to death: having things sorted out before I die; issues to be faced; time left; to have one good Christmas with the kids	28 (5)	
	21 (7)	Independence, choice	33 (6)	
	15 (5)	Work	6 (1)	
Having somewhere to live, a home	12 (4)			
Sex, lover, sexuality	12 (4)			
	12 (4)	Leisure pursuits	17 (3)	
	9 (3)	Living conditions	33 (6)	
	9 (3)	Spirituality	28 (5)	
Getting work	6 (2)			
	3 (1)	Miscellaneous	6 (1)	

case group only. Issues relating to death, such as "the amount of time I have left" or "having everything sorted out before I die" featured for the case group only and—not surprisingly in a young and healthy population—did not feature for the comparison group at all.

In general, different cues were nominated by the gay group and injecting drug users (table 2). For injecting drug users, family was nominated most frequently, followed by health, drugs and drug related issues, and money (frequently also related to purchasing drugs). For the gay group, health, friends and social life, and psychological issues such as self acceptance and sense of control were nominated with equal frequency.

Table 3 compares the cues of those within the case group who were asymptomatic (Centers for Disease Control stages II or III) and those with symptoms (stage IV or with an AIDS defining illness). The cues nominated by these two groups differed minimally from one another, and the frequency with which the various life areas were nominated was broadly similar.

Conclusions

The key feature of the SEIQoL methodology is its relevance to the individual; this is assured because the respondent defines the areas to be measured. This feature is maintained in the abbreviated version of the methodology described here. Administration of the SEIQoL-DW is relatively simple and requires minimal training, available in the form of a manual from the authors.[12]

In this first clinical application, the SEIQoL-DW was found to be acceptable and practicable in a population that is difficult to study. It highlighted differences in key issues of quality of life identified by gay and drug using HIV positive patients and showed unexpected similarities in the key issues nominated by the asymptomatic and symptomatic HIV groups. The measure took about five or 10 minutes to complete and proved to be practical in busy clinical contexts. Its flexibility and patient centred approach make it appropriate not just for HIV related problems but potentially for many other chronic illnesses dealt with in general practice. It should also

prove possible to incorporate the SEIQoL-DW into large scale clinical trials as an adjunct to health status measures.

We believe that the SEIQoL-DW has a potentially important role to play in the consultation process. By eliciting the patient's cues and their current status on and the relative importance of each, the health care team is in a better position to formulate and monitor therapeutic plans. Such information may also serve to heighten the patient's self awareness and to increase carers' insight of the patient's view of a situation. The measure should improve communication and facilitate joint decision making, leading to increased patient satisfaction and consequently to increased commitment and adherence to treatment.

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Lessons from international experience in controlling pharmaceutical expenditure III: regulating industry

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This is the third of three papers that review international policies to control spending on drugs and to improve the efficiency of drug use. This paper reviews policies regulating the supply of drugs, particularly licensing and reimbursement controls, price and profit regulation. Price and profit controls contain few incentives for improving cost effective use of drugs, and focus on cost containment and profitability of domestic industry. Carefully monitored economic evaluation could lead to improvements in efficiency and benefits to patients and the health care system.

In this series of three papers we describe recent policies to control spending on drugs in several developed countries which can provide insights for British health policy. We also examine rigorous evaluative studies, where they are available, to assess the impact of these policies on prescribing. Details of our literature search are in the first paper in our series.

In this paper we review policies intended to regulate the behaviour of drug manufacturers, particularly governments' control of licensing, reimbursement, and prices and profit. Previous papers have examined policies aimed at influencing the behaviour of doctors and of patients.

Licensing and reimbursement

Most countries require evidence of efficacy and safety for licensing new drugs, but none requires evidence of cost effectiveness. Licensing may be "ultimately the most powerful economic control as it can exclude products from the market,"[1] and an increasing number of countries include economic factors when deciding whether to reimburse products. Many governments may restrict publicly reimbursed drugs by positive lists (Australia, New Zealand, Italy, France) or negative lists (Germany, Ireland, the Netherlands, Spain, United Kingdom). Decisions are based on information about safety and efficacy, professional opinion, and, occasionally, cost effectiveness. Australia and the province of Ontario in Canada were the first to include data on cost effectiveness data in decisions about reimbursement. France, Britain, and the United States have also implemented some policies to encourage the provision of economic data. The objective of these policies is to increase the cost effectiveness of the use of drugs, but the approach between countries has varied.

Since 1993, drug companies have been required to include an economic evaluation in applications for reimbursement through the pharmaceutical benefit scheme in Australia.[2 3] New drugs with no demonstrable advantage over existing products are offered at the same price. Where clinical trials show superiority, incremental cost effectiveness is assessed to determine whether a product represents value for money at the price sought. While the deliberations of the advisory committee are confidential, some recommendations have received press coverage, such as failure to agree prices for sumatriptan and salmeterol and rejection of applications to list finasteride for prostatic hypertrophy and DNAse for cystic fibrosis. In some cases economic analyses have been used to justify higher prices than might have been achieved before economic criteria became mandatory.[4]

In October 1991 Ontario published draft guidelines for economic analyses that were to be included in submissions for listing in the Ontario formulary.[5-7] During 1992 the Canadian Coordinating Office for Health Technology Assessment developed a set of guidelines that each province in Canada could adopt as it saw fit.[8] These guidelines have evolved through a broad consultative process.[4]

In France reimbursement is reviewed by the Transparency Commission and a Drug Economic Committee. About a third of submissions includes a pharmacoeconomic study.[9] The final price offered takes into account the characteristics of the company and expected benefits to the economy. The hospital sector negotiates prices directly with manufacturers. The United States Food and Drugs Administration has published principles for the review of pharmacoeconomic studies,[10] and the American drug industry association has developed voluntary guidelines for measuring the cost effectiveness of drugs.[11] The Health Care Financing Administration also includes cost effectiveness criteria for determining reimbursement under Medicare.

The British government is encouraging the use of economic evaluation of new drug products, by agreeing voluntary "guidelines for the economic evaluation of pharmaceuticals"[12] with the Association of the British Pharmaceutical Industry. Manufacturers are not required to submit economic evaluations either for licensing or reimbursement purposes.

Price controls

Governments commonly set prices for drugs, and many countries have cut prices. Britain is unique in allowing freedom of pricing but controlling prices indirectly by setting target profits. In Britain a 2.5% cut in profit targets was negotiated in 1993, and prices of existing products were frozen until 1996.

REFERENCE PRICING

In reference price systems, a reimbursement price is set for a therapeutic category of drugs and patients pay any difference between the cost of the product prescribed and the reference price. The reference price may be the average price of drugs in a category (the Netherlands,[13] Germany[14]), the lowest priced drug (New Zealand), or the lowest priced generic drug plus

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