

Article

Quality-of-Life Outcomes Assessment

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Quality-of-life outcomes assessment represents the functional effect of a diagnosis and its consequent therapy upon a patient, as perceived by the patient. This concept is not new to behavioral optometrists, who monitor changes in patients' performance resulting from behavioral vision care. However, the Era of Assessment and Accountability in medical care has created the need for standardized measurements of quality-of-life outcomes. COVD's Quality of Life Outcomes Assessment Committee has designed a questionnaire to measure changes in quality of life associated with vision therapy. **Key Words:** *quality of life, outcomes assessment, Assessment and Accountability, health care reform, health profile, standardized.*

Quality-of-life outcomes assessment represents the functional effect of a diagnosis and its consequent therapy upon a patient, as perceived by the patient.¹ This concept is not new to behavioral optometrists, who constantly monitor patients' behaviors and performance, and look for positive changes that result from behavioral vision care. Less familiar to optometrists is the knowledge and expertise that has evolved in the application of quality-of-life concepts to the measurement of outcomes.

Evaluation of the quality of life has always been a part of medical practice, beginning when the doctor asks the patient, "How are you doing?" This informal, unstructured evaluation directs the doctor toward the patient's chief complaint and concerns regarding treat-

ment. The doctor, therefore, acknowledges that the patient's perspective is an essential part of providing quality medical care. Every patient brings a unique set of values, expectations, and experiences to the doctor-patient encounter. Two patients with the same physical findings are likely to have very different responses to the question, "How are you?" For example, a 24-year-old full-time student with a convergence insufficiency reveals that his/her quality of life is significantly affected by the vision problem when complaining of constant headaches, intermittent diplopia, and great difficulty concentrating when reading. A 24-year-old bus driver with a convergence insufficiency has no subjective complaints. The vision problem has had virtually no impact on his/her quality of life. Management of these patients will differ, reflecting their individual needs.

However meaningful and insightful the patient's responses are, this type of evaluation of quality of life has limited application. Al-

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though it enables us to assess individual needs and make management decisions, it cannot be applied to groups of patients. Quality-of-life concepts must be quantifiable to be used for evaluating treatment modalities or comparing experimental and control groups.

Quality-of-life outcomes assessment is the quantification of these subjective concepts and their application to clinical trials.² Measuring quality of life, is no easy task, however. Many would argue that every person has their own individual conception of quality of life, which defies quantification. Hoffman and Rouse³ summarize the key issues: Which aspects of peoples' lives should be measured? What type of measurement instruments should be developed? What can we hope to gain by measuring quality of life?

WHAT SHOULD WE MEASURE?

Faden and Leplege⁴ conceptualize the relationship between quality of life and medical care as a two-way street.

On the one hand, a person's pre-existing, general quality of life may have direct bearing on decisions about treatment. At the same time, although health states and the interventions that produce them can have a significant impact on life quality, they are among many factors determining a person's quality of life.

One response to this problem of measuring a complex concept has been to create a one-way street called health-related quality of life, which focuses on the impact of health states on quality of life. This may narrow our scope, but it does not answer the question, "What should we measure?" As health-related quality of life has evolved from a philosophical discussion to an empirical evaluation of patient status to a quantifiable health index, what has emerged is a common ground which has become the basis for the evaluation of health-related quality of life. This common ground may be represented as four domains¹:

1. Physical and occupational function including issues such as mobility, self-care, household management, job and school requirements.
2. Psychological state including anxiety, spiritual well-being, sleep and rest, and life satisfaction.

3. Social interactions including interpersonal relationships with family and community.
4. Somatic sensation including symptoms associated with treatment as well as the illness.

WHAT CAN OPTOMETRY GAIN?

Why does optometry need to be concerned with quality-of-life outcomes assessment? Relman⁵ has called the outcomes movement "the third revolution in health care," the logical consequence of the first and second revolutions. The Era of Expansion, which began after World War II, was characterized by rapid growth in facilities, technology, and medical specialties. The creation of Medicare and Medicaid in 1966 brought health insurance to 85% of Americans, and health care became an industry. The rebound was the Era of Cost Containment, as third-party payers, employers, and the federal government balked at the bills. The result was managed care and the birth of the health care executive. As health care executives and government regulators put policies in place to control costs, patient concerns about the quality of care have increased. Physicians lament their loss of autonomy in making decisions concerning appropriate care. Third-party payers wonder what their dollars are buying. The answer to "uninformed patients, skeptical payers, frustrated physicians, and besieged health-care executives"⁶ is the third revolution—the Era of Assessment and Accountability. Outcomes assessment, the technology for the third revolution, is designed to help patients, payers, players, and providers make rational health care-related choices based on better insight into the effect of these choices on the patient's life. More and more, physicians are being asked for an assessment (Prove to me that it works.) and an accounting, (How long will it take and how much will it cost?).

Outcomes assessment technology is being applied to compare the effectiveness of various interventions, help patients and providers make more informed decisions, guide the payers in appropriating the use of resources, and develop clinical guidelines for patient management.⁶ These are some examples of these applications, from both the public and private sectors.

- In 1989, the federal government established the Agency for Health Care Policy and Research (AHCPR) to enhance the quality, appropriateness, and effectiveness of health care services.⁷ In 1990, AHCPR's budget was \$30 million. In the 1996 budget, their budget is projected at \$202 million.
- Within AHCPR, the Office of the Forum for Quality and Effectiveness in Health Care has, as its mission, the development of clinical practice guidelines. To date, 10 guidelines have been published including *Cataract in Adults: Management of Functional Impairment*.⁸ Health professional associations, including the American Optometric Association (AOA), have followed suit. AOA has published seven Clinical Practice Guidelines,⁹ with an additional six under development.
- A Medline search of all articles pertaining to health-related quality-of-life outcomes revealed 28 articles published in 1990. The same search for articles published in 1994 yielded 192 citations.
- Federal health programs have expanded their focus beyond administration and finance. The Health Care Financing Administration has been analyzing its data on Medicare beneficiaries to assess the impact of medical intervention on health outcomes.¹⁰

Thier¹¹ advised the clinician to "face the issue up front." Accepting the fact that these methods will be used to monitor and evaluate care and to structure reimbursement becomes the first step in recognizing their potential value in the clinical setting.

Trust. These tools can help the optometrist focus on the reasons the patient sought behavioral vision care, beyond what might be communicated during the standard case history. At a time when patients are becoming increasingly frustrated by an impersonal health care system, the capacity of the optometrist to relate patient needs to treatment objectives can strengthen the doctor-patient relationship.

Access. Thier notes; "If we had better measures of effectiveness and could make more precise choices, then we might be able to direct resources toward those better choices.

If, further, these were less expensive choices, we might then increase access to care."¹¹

Quality Care. Quality-of-life measurements can have an impact on the quality of care both directly and indirectly. The patient's subjective judgments provide important information which is not available from clinical data. In problem-oriented records, subjective (S) notes include information provided by the patient concerning symptoms, compliance, and new concerns. Objective (O) notes include clinical data. These are considered together to derive an assessment (A) and management plan (P). The SOAP format improves the quality of care by structuring the clinician's clinical thinking.¹² Quality-of-life outcomes assessment can also provide comparisons of various interventions. Enhancing optometrists' ability to educate patients concerning the impact of alternative treatments allow the patient to make more informed decisions, which also improves the quality of care.

WHAT TYPE OF MEASUREMENT INSTRUMENTS SHOULD BE DEVELOPED?

Before deciding what type of measurement instruments should be developed, it is important to consider what is presently available. There are primarily two types of health-related quality-of-life assessments: general health profiles and disease-specific measures. A general health profile is nonspecific, addressing a wide range of quality-of-life issues. Examples include the Medical Outcome Study Health Status Questionnaire (SF-36)¹³ which has 36 items and takes 10 minutes to administer, and the Sickness Impact Profile,¹⁴ which has 136 items and takes 30 minutes to administer. Their advantage is their application to various populations and diseases. Their disadvantage is their nonspecificity and they are often unable to measure specific changes in patients with specific problems.

Disease-specific measures assess quality of life relative to specific conditions and their subsequent treatment. Examples include arthritis, cancer, and heart disease,¹⁵ as well as cataracts¹⁶⁻¹⁹ and binocular vision dysfunction.²⁰ Although these scales have proven invaluable in measuring the quality of life associated with specific conditions, they also have

Please assign a value between 0 and 4 for each symptom.
 0 = never or non-existent / 1 = seldom / 2 = occasionally / 3 = frequently / 4 = always

| | | |
|-----|---|--|
| 1. | blurred vision at near | |
| 2. | double vision | |
| 3. | headaches associated with near work | |
| 4. | words run together when reading | |
| 5. | burning, stinging, watery eyes | |
| 6. | falling asleep when reading | |
| 7. | vision worse at the end of the day | |
| 8. | skipping or repeating lines when reading | |
| 9. | dizziness or nausea associated with near work | |
| 10. | head tilt or closing one eye when reading | |
| 11. | difficulty copying from the chalkboard | |
| 12. | avoidance of reading and near work | |
| 13. | omitting small words when reading | |
| 14. | writing uphill or downhill | |
| 15. | misaligning digits in columns of numbers | |
| 16. | reading comprehension declining over time | |
| 17. | inconsistent/poor sports performance | |
| 18. | holding reading material too close | |
| 19. | short attention span | |
| 20. | difficulty completing assignments in reasonable time | |
| 21. | saying "I can't" before trying | |
| 22. | avoiding sports and games | |
| 23. | difficulty with hand tools-scissor, screwdriver, calculator, keys | |
| 24. | inability to estimate distances accurately | |
| 25. | tendency to knock things over on desk or table | |
| 26. | difficulty with time management | |
| 27. | difficulty with money concepts, making change | |
| 28. | misplaces or loses papers, objects, belongings | |
| 29. | car sickness/motion sickness | |
| 30. | forgetful, poor memory | |

Fig 1. Questionnaire evaluating performance of patients with accommodative/vergence dysfunctions.

a major disadvantage. Their specificity limits their ability to compare the effects of different diseases or management alternatives.

Hoffman and Rouse³ reiterated a theme developed by Patrick and Deyo¹⁵ on the need to combine both disease-specific and general measures of quality of life when designing optometric clinical research. The vision-specific scale establishes a baseline and increases the likelihood of identifying changes in quality of life over time. A standardized general measure of quality of life facilitates comparisons with other conditions and populations. There are many general quality-of-life instruments available which are standardized, valid, and reliable. On the other hand, the amount of research examining the relationships between vision and quality of life is minimal; the emphasis has been on disease.

Brennen et al¹⁶ measured changes in quality of life associated with the treatment of various ocular conditions, including cataracts, glaucoma, and macular degeneration. They concluded that whenever visual function improved (regardless of the disease or the treatment), quality of life improved. When visual function declined (either from disease progression or treatment complications), quality of life also declined. Mangione et al¹⁸ developed the Activities of Daily Vision Scale (ADVS), a questionnaire that measures the patient's perception of functional impairment during activities such as driving, watching television, reading the newspaper, and preparing meals. The ADVS is a valid and reliable measure of visual impairment caused by cataracts. Improved visual function after cataract surgery was associated with a better health-related quality of life 1 year after the surgery.¹⁹ Cooper et al²⁰ used a seven-item questionnaire to measure aesthenopia in patients with convergence insufficiency, before and after vision therapy. The questions were very focused, looking only at nearpoint symptoms. Vision therapy resulted in both increased fusional ranges and decreased symptomology, demonstrating an improved quality of life associated with a specific treatment option.

The approaches of Mangione and Cooper to evaluating the quality of life and vision represent two extremes. Mangione's ADVS is directed at function, but it lacks the specificity required to measure changes associated with

vision therapy. Cooper's aesthenopia survey is too limited, ignoring many behaviors and performance areas relevant to behavioral vision care. Therefore, to begin considering the relationship between quality of life and vision therapy, an instrument that is applicable to optometric vision therapy must be developed.

THE COVD QUALITY-OF-LIFE OUTCOMES ASSESSMENT COMMITTEE

The College of Optometrists in Vision Development established a Quality of Life Outcomes Assessment Committee to begin investigating some of these issues and to educate the membership. After surveying the literature, it was determined that no instrument presently exists that can be used by behavioral optometrists to measure outcomes of vision therapy. The first project undertaken was the development of a survey that could be used by the membership to measure objectively the subjective changes in patients' behaviors and performance associated with vision therapy. To accomplish this, some ground rules were established.

1. This is a dynamic process. It is more important to begin collecting data than to wait until we have the perfect instrument. We can always refine anything we develop, but we need the feedback to maximize its clinical relevance.
2. Be practical. It is unrealistic to expect the doctor or the patient to be filling out forms or conducting interviews for any length of time.
3. Keep it simple. Start with more common, less complex case presentations to maximize its clinical application.

Using these ground rules, it was decided to develop a one-page questionnaire (Fig 1) to evaluate performance of patients with accommodative/vergence dysfunctions before and after vision therapy.

A letter was sent to the membership asking for copies of surveys and questionnaires being used to evaluate changes patients were reporting during and after vision therapy. All the surveys were then examined and blended together to develop a questionnaire to quantify changes in performance.

The next step in the process of measuring outcomes is feedback. Please use this ques-

tionnaire in your practice. If you administer the survey pre- and post-therapy, can you measure a change? Are there aspects of performance that are missing? Are some of the items redundant? How can the survey be improved or made more applicable to patient care?

CONCLUSIONS

The American health care system is careening out of control as patients, physicians, payers, and players each attempt to bring their own unique perspective to bear. Quality-of-life outcomes assessment, the technology of the third revolution, is the opportunity to level the playing field. Forcing all decisions to be made from a common patient-based framework could help create order and a greater sense of justice. For behavioral optometrists, this is a golden opportunity. Our profession has always stressed the positive changes in performance resulting from vision therapy. Quality-of-life outcomes assessment will allow us to measure objectively what we have always known to be true.

In his book *Technotrends* Burris wrote, "If the technology exists, it will be used."²¹ Clearly quality-of-life outcomes assessment will have great impact on optometry and all the health professions. If optometrists do not play this card, then the payers and the players will. But rather than focus on defense, every clinician should take an offensive position. We should all strive to bring a better quality of life to our patients.

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