

## QUALITY OF LIFE MEASUREMENT IN LEARNING DISABILITY: BASIC ISSUES

*Interest in quality of life assessment was stimulated in the late 1940's after the World Health Organisation defined health as "a state of complete physical, mental and social well-being and not merely the absence of disease" (WHO, 1948). Progress towards reliable and valid measures has been slow owing to the difficulties in obtaining objective data and in making the definition operational. Health related quality of life has been defined as the level of well-being and satisfaction associated with events or conditions in a person's life as influenced by disease, accidents or treatments (Patrick and Erickson, 1987). This considers not only functional ability but degree of satisfaction derived from the performance of social roles and activities. It ranges from everyday necessities of life such as food and shelter to those associated with achieving a sense of fulfilment and personal happiness.*

*Jenkins (1990) has described important outcome indicators in learning disability, some of which are also applicable to other specialities. These include age at death, hospital admission and readmission rates, uptake of day and respite services, additional handicaps and "estimates of consumer satisfaction" (the latter emphasizing the difficulty in obtaining accurate information in quality of life assessment). Indeed measurement in learning disability presents a unique challenge. Obtaining details directly from patients is difficult and*

*"hard data" outcome measures are scarce (e.g. the frequency of aggressive outbursts requiring restraint or the number of daily excursions from the residence). Although quite valuable, even these examples could be inaccurately recorded. Besides, relying only on "hard data" provides an incomplete picture. Health professionals too, while expressing interest in quality of life measures, find it difficult to integrate any objective findings to modify clinical practice.*

*However, attitudes are changing as quality of life takes an increasingly prominent role in cost-utility analysis and audit. Nonetheless, detailed systematic assessment remains largely the domain of researchers studying groups or populations rather than clinicians screening or monitoring individual patients in routine practice.*

*The relocation of long-term hospitalized patients with learning disability in the community and the philosophy of "normalization" (Wolfensberger, 1972) aim to improve quality of life. Indeed much of the clinical work of learning disability multidisciplinary teams is directed at improving the adaptive functioning and life satisfaction of their patients.*

*This brief paper considers quality of life assessment in learning disability, exploring some of the pitfalls and possibilities in measurement and instrument selection.*

## Measurement Problems

The measurement properties of a chosen instrument can be assessed in terms of validity, reliability and standardization.

### 1. Validity:

No "gold standard" or clearly defined objective criteria exist to validate instruments in learning disability (construct validity). Therefore, subjective judgements are made as to the social value of a particular behaviour and which quality of life dimensions (defining parameters) merit assessment. Many dilemmas exist. For example, freedom of choice (central to the concept of normalization), is not synonymous with quality of life. The patient with learning disability, faced with too many options may become very distressed, while a more structured timetable may better meet the patient's needs and wishes. Indeed, a scale which has good face validity for the general population may be inappropriate in learning disability. Also, as dimensions are often a very indirect behavioural analogue of a component of quality of life, findings can be misleading. The group home resident who is noted to be spending increasing periods involved in social activities out with the home could be doing this for negative reasons (e.g. a deteriorating relationship with another resident or the wish to obtain alcohol) yet this behaviour may score well on a "community involvement" dimension.

Tests which can effectively identify future needs can have an important effect on resource planning (predictive validity).

### 2. Reliability:

As much of the rating is highly subjective, inter-rater reliability is particularly important. In view of limited hard data, it may also be unclear whether test/retest reliability reflects measurement error or real change. Questions pertaining to assess the same dimension may be answered in opposite ways (poor internal reliability). Indeed, owing to reliability problems, several brief assessment schedules are better utilized in large population studies than in the assessment of needs of individuals, as large numbers dilute error in such short tests. Nonetheless, as much information is gathered from an informant well acquainted with the patient, well structured tests which define their assessment parameters clearly can demonstrate considerable consistency across observers and on serial testing.

### 3. Standardization:

Many scales have not been standardized, often because they were developed for a specific purpose where it would be meaningless or impossible to identify an appropriate standardization sample.

There are two main approaches: standardization against a large sample from the general population or from the learning disability population. In the former case, it might be argued that the general population function too well to represent a meaningful group for direct comparison, therefore it becomes an arbitrary decision what level of functioning for the mentally impaired person or group is appropriate.

Knowledge of scores for the general population, of course, can assist in setting realistic goals for the impaired individual. Comparison to the learning disability population provides useful information on how a patient performs in relation to his peers, particularly where standardization samples are broken down by ability level. As it is not known whether others are functioning maximally, it becomes unclear which individuals should be targeted for further intervention with a view to improving function. Such a sample, however, would appear a more appropriate comparison group as one could more easily identify resource needs for different service areas determined by their scores in relation to national 'norms'.

## **Instrument Selection**

### **1. Administration of test:**

More information can be obtained by interview, than by self-assessment. Wherever possible, the respondee should be the patient but often staff or "advocates" acting for the patient need to be involved. This can introduce considerable loss of objectivity: staff may be unrealistically positive, lest it reflect badly on their care while a well meaning advocate may have unrealistic expectations of the patient, so being too negative. Also, as carers generally have prior warning of pending assessments and the opportunity to modify life-styles, the Hawthorn effect may distort results. Nonetheless, carers have often known the person with learning disability for several years and will be very clear about his abilities and range of current activities. Of course, such a long-term relationship can

lead to an unnecessary maintenance of the status quo without facilitating personal development. Systematic review, with particular emphasis on quality of life, reduces the possibility of the familiarity hindering constructive change.

The timing of assessments is also critical, particularly at follow up after an intervention aimed at improving a particular dimension of quality of life. For example, if the frequency of fits is successfully reduced by an alteration in anticonvulsant medication, how soon should "quality of community contact" be reassessed given that improvement might be delayed until confidence is restored?

### **2. Management issues:**

Staff resources and training facilities, when limited, will obviously make lengthy tests impractical. Nonetheless, careful liaison with other disciplines, particularly social work departments responsible for staffing community homes and hostels, is essential. The existing workload of multidisciplinary team members makes it difficult to launch new initiatives which could further stretch manpower resources. There are also major logistic problems given that each discipline has its individual line management structure with differing philosophies and resources. Besides, should it become apparent that many individuals are inappropriately housed, in the absence of resources to relocate them, such information is of limited worth. Even the identification of new areas for time limited intervention by trained staff may pose unrealistic demands on the service. If teams

anticipate these difficulties, they may be less inclined to embark on quality of life assessment. Nonetheless, if such assessment allows a more focussed clinical input, time may be saved in the longer term.

### 3. Nature of instrument:

The choice of instrument depends on the nature of the assessment task.

#### A) Generic Tests

A generic instrument, not specific to learning disability allows comparisons between different disease groups but puts insufficient emphasis on critical dimensions in learning disability. Such loading could misrepresent the problems of a learning disabled person. Besides, as these instruments aim to detect deviations from normal adult function, it is difficult to detect change within individuals or make adequate comparisons between groups in the low scoring learning disability patients. Nonetheless, a broad approach may yield unexpected findings.

#### B) Tests specific to learning disability

There are, of course, a vast array of assessment measures, each designed for a specific purpose. Some short tests can be completed within a few minutes but are only useful for screening. Longer assessments are needed to draw up individual case plans. Such detailed tests can take more than 12 hours to complete but newer assessments which are much quicker to apply and do not require specific training have recently been developed.

The choice of instrument depends on the characteristics of the population under

study. Patients with physical handicaps and mobility problems need a more detailed assessment of, for example, access arrangements, while a group home resident would need more detail on community involvement and social interaction than a hospital resident.

Assessment measures must be pitched at the appropriate ability level: for example, an able subject may continue to score highly on a scale designed for less able subjects despite a considerable reduction in functioning.

As many former long-term hospital patients are resettled in community group homes, assessment of quality of life in these individuals has attracted increasing attention.

What are the key quality of life dimensions in learning disability? In other words, which important areas of life experience define a subject's level of adaptive functioning and should be measured?

These can be summarized as follows:

1. The opportunity to make and sustain relationships.
2. Freedom and diversity of choice.
3. The maintenance of personal dignity and individuality.
4. Community involvement.
5. Continuing personal development through appropriate support and training.
6. Regular recreational activities.
7. A safe and pleasant home environment.

Most comprehensive quality of life assessment measures effectively cover these areas. As already discussed, validity, reliability, standardization, ease of administration and nature of assessment

task also influence the choice of instrument.

The ideal test has the following characteristics:

1. Brevity and ease of application without specific training.
2. Previously demonstrated validity and reliability in the same context, covering the key areas as listed above.
3. Standardization against comparable

populations.

4. Results presented in a clinically useful form, requiring minimal further analysis.
5. Prior agreement between teams and other centres to use the same measure to allow comparisons between areas.

Some commonly used assessment measures are summarized in TABLE I.

**TABLE I**  
**Key characteristics of commonly used Quality of Life measures.**

Ratings are: Validity (Val.), Reliability (Rel.), Standardization (Stand.) and Ease of administration (Admin.)

Instrument	Typical use	Val.	Rel.	Stand.	Admin.
Sickness Impact Profile (Bergner <i>et al.</i> , 1981)	Generic Assessment	+	++	-	++
Wessex Behaviour Rating Scale (Kushlick <i>et al.</i> , 1973)	Screening, Service Development	++	+	-	+++
Life Experience Checklist (Ager, 1989)	Screening	+	+	++	++++
Adaptive Behaviour Scale (Nashira <i>et al.</i> , 1969)	Individual Patient Programming	+++	++++	+++	+
COMPASS (Cragg and Look, 1992)	Individual Patient Programming	++	+	-	+++
Hampshire Assessment for Living with Others (Shackleton-Bailey and Pidcock, 1983)	Profoundly Physically Handicapped needs	+	++	-	+
Disability Assessment Schedule (Holmes <i>et al.</i> , 1982)	Screening Planning	+	+++	-	++
<p>KEY:</p> <ul style="list-style-type: none"> <li>- Not available</li> <li>+ Limited information/poor</li> <li>++ fair</li> <li>+++ good</li> <li>++++ very good</li> </ul>					

For a full review of common tests, schedules and checklists in learning disability, including some of those above, the reader is referred to a guide edited by Hogg and Raynes (1987).

## **Discussion**

Health professionals may choose a variety of process and outcome measures to assess the effects of their interventions and set new procedural standards in routine audit. However, what matters to the patient is the effect on his or her quality of life. If we fail to consider quality of life issues, we cannot assume our treatment is optimal. This is particularly relevant in learning disability where there are few "hard" outcome measures and patients may not always be relied upon to report problems. Consequently, we must assess the patient's quality of life and not our perceived quality of life for him. Also, what is best for the non-handicapped is not automatically so for the handicapped. We therefore require reliable, clinically validated and standardized measures, sensitive to change within individuals. However, assessment of quality of life yields subjective, "soft" data, and there are problems in choosing an appropriate standardization sample. Of course, we must also consider physical parameters. Quality of eyesight or hearing, for example, are directly relevant.

Current clinical practice typically has no systematic assessment of quality of life outcome following interventions in daily practice. If we are to integrate routine tests, they need to be easy to administer and analyse, yielding data in a useful form. They

cannot, however, be so brief as to lose information on vital dimensions. Time spent on careful assessment is rarely wasted. Unfortunately, many remain uncertain as to the relevance of quality of life assessment.

If learning disability teams are to become more involved in monitoring quality of life, informal meetings are required to raise awareness and agree upon appropriate assessments for the patient group under study (e.g. in routine audit). This is particularly important where the model or philosophy of care delivery of the usual care giver differs from that of the investigator. Even with such preparatory steps, other disciplines may find systematized review intrusive unless fully involved in the assessment process and interventions to address identified need.

## **Conclusion**

Quality of life measures in learning disability are important. Although existing tests are continually refined and new assessments developed, we are still in the early stages of evolving reliable measures for routine use. While a multi-disciplinary approach is required, assessment is only valid if patient centred. Simplicity is important as cumbersome data cannot easily be linked into audit.

Clearly, there is a need for further research to validate existing measures and assess their use in day to day practice. A high priority must be given to further research given the fundamental link between quality of life and health status.

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