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Quality of Life Measurement in Persons with Schizophrenia: Are We Measuring What's Important?

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INTRODUCTION

Quality of life measurement for people with schizophrenia has become increasingly important for both clinical practice and evaluation research. The goals for treating individuals with schizophrenia have changed radically as treatment has shifted from a hospital-based to a community-based system. In traditional systems, symptom reduction was considered the major goal. While this objective remains important in community-based systems, the ability to live a stable life in the community has become a primary goal. For people with schizophrenia, achieving a good quality of life (QoL) is often their most important goal. Furthermore, improving QoL has achieved a second role as an important indicator of treatment outcome (Baker, 1995; Lehman, 1995; Cheung, 1997; Durbin *et al.*, 2003). In tandem with a shift in treatment goals within mental health and increasing pressures for greater system accountability, there has been an exponential increase in the use of QoL outcome evaluation. Nonetheless, confusion continues over its definition and measurement. There remains no 'gold standard' for QoL measurement in psychiatry and little information exists about what changes in scores mean in terms of clinical improvement or deterioration, or what relevance they hold for consumers or service managers (Juniper *et al.*, 1994; Cramer *et al.*, 2000; Moos, Nichol and Moos, 2002). In addition, QoL researchers have been criticised, when purporting to assess the impact of treatment, for their failure to use appropriate measures that incorporate concerns of consumers and their families (Awad *et al.*, 1995; Lefley, 1996; Fischer, Shumway and Owen, 2002). There is now growing interest in having standards for measurement and using QoL questionnaires, both to improve clinical practice and provide accurate evidence of outcomes from the consumer's point of view (Gill and Feinstein, 1994; Becker, 1998; Garratt *et al.*, 2002).

After reviewing concerns about QoL measurement and treatment outcomes for persons with schizophrenia, this chapter presents a new approach to QoL assessment.

SCHIZOPHRENIA

Schizophrenia is a prolonged mental disorder that usually begins before the age of 25 and persists throughout life. Research demonstrates that the eventual course and outcome are much more heterogeneous

than was previously thought (Harding, Zubin and Strauss, 1987; Leff *et al.*, 1992; Bermanzohn *et al.*, 2001). The traditional view was that this disorder led to a persistent, downhill course of increasing disability and decreasing QoL, but we know now that the course is often erratic, with periods of relatively good functioning mixed with relapses and decreased function. Often, the pattern is unpredictable. Recent research shows that associated psychiatric syndromes (depression, substance abuse, obsessive–compulsive disorder and panic disorder) co-occur with schizophrenia at significant rates. Unfortunately, these syndromes frequently go unrecognised, undiagnosed and untreated. Their presence may contribute to and help to explain the heterogeneous levels of recompensation and change reported in outcome studies (Siris, Bermanzohn and Kessler 1997). Although the reported prevalence rates of associated psychiatric syndromes (APS) in persons with schizophrenia have varied considerably, estimates have all been substantial. Bermanzohn, Porto and Siris (2000), as well as Harvey (2005), found that the lifetime rates of depression, obsessive–compulsive disorder and panic disorder in persons diagnosed with schizophrenia were 54.2, 59.2, and 29.5%, respectively. Soni *et al.* (1992) found that persons with schizophrenia living in the community had more depression and anxiety than those living in the hospital and attributed this to the greater stress and lowered QoL reported for this vulnerable population.

While a cure is not now a realistic goal for most persons (Hegarty *et al.*, 1994), long-term outcome studies show that a substantial proportion of people with schizophrenia have a good to excellent long-term prognosis (Carpenter and Strauss, 1991; Musser *et al.*, 1997; Siris, 2000). Research also suggests that some people recover and become symptom free, no longer needing medication or other treatment, although we know little about what promotes this recovery (Ciompi, 1980; Warner, 1985; Strauss, 1994). As with many chronic illnesses, the main treatment goals are to maintain function, promote recovery and maximise QoL.

Given the prolonged nature of the illness, the complexity of treatment and its cost to society, to determine which individuals are improving and which are not, it is critical to use appropriate outcome measurements that incorporate the concerns of consumers. To develop better treatment programmes, it is necessary to know which are effective and what circumstances are required to assure their effectiveness.

QUALITY OF LIFE AND DEINSTITUTIONALISATION

In the United States, interest in QoL and the social disabilities associated with schizophrenia intensified in the wake of the deinstitutionalisation of the late 1960s and early 1970s, with the wholesale transfer of psychiatric patients into the community, where they have become increasingly visible.

In support of deinstitutionalisation, a number of research projects demonstrated that appropriate community-based treatment and support could increase QoL (Stein and Test, 1987; Levitt, Hogan and Bocosky, 1990; Lehman, Slaughter and Myers, 1991; Sullivan, Wells and Leake, 1991). Too often, however, appropriate supports were not provided and people with schizophrenia were ejected from hospitals and abandoned in communities (Shadish and Bootzin, 1981; Mechanic, 1986). Although this transfer out of hospitals was claimed to be partly justified as improving peoples' lives, over time it became apparent that it did not automatically improve anyone's life.

Research shows that community-dwelling persons with schizophrenia are among the psychiatric patients with the lowest overall life satisfaction scores in the general population (Lehman, Possidente and Hawker, 1986; Rosenfield, 1992). Quality of life, at least for some persons, was worse in the community than in long-stay hospitals (Schmidt *et al.*, 1977; Lamb, 1979, 1981). Research shows that deinstitutionalised individuals often live in substandard housing (Bachrach, 1982; Uehara, 1994), are dissatisfied with their finances, employment, social relationships and personal safety (Lehman, 1992), and are over-represented in the homeless population (Bassuk and Lamb, 1986; Rossi and Wright, 1987; Drake, Wallach and Hoffman, 1989; Rosenheck, Bassuk and Salomon, 1999).

During the early phase of deinstitutionalisation, the primary concern was hospital recidivism. How could tenure in the community be extended and stabilised? Over time, it became increasingly evident that just being out of the hospital was not enough (Bachrach, 1982, 1987; Solomon, 1992). Living situations and levels of despair that had been accepted in hospitals were less tolerable in the community. Reported poor QoL conditions and marked social disabilities caused alarm, generating a sustained

interest in targeting treatment towards these issues and developing guidelines for treatment (Stein and Test, 1985; Hadorn, 1993; Stein and Santos, 1998; Milner and Valenstein, 2002; Ridgely *et al.*, 2002). Concerns about the effects of deinstitutionalisation stimulated a substantial body of research on the correlates of successful adaptation and psychiatric rehabilitation (Anthony and Farkas, 1982; Avison and Speechley, 1987; Carpenter and Strauss, 1991; Strauss, 1994; McGrew, Wilson and Bond, 2002).

Over time, clinicians working in the community gained a better understanding of the centrality of QoL concerns. They began to recognise that an individual's subjective experience of QoL affects motivation to seek treatment and to continue with medication and rehabilitation (Hogan, Awad and Eastwood, 1983; Diamond, 1985; Diamond and Becker, 1999; Awad *et al.*, 1995). Some have even speculated that an individual's perception of his/her life quality may influence the phases and course of the illness (Strauss, 1989).

As a consequence of the profound shift in thinking about the abilities, needs and aspirations of community-living persons with schizophrenia, improving their QoL emerged as the major goal of community treatment (Baker and Intagliata, 1982; Rosenfield, 1992; Becker, 1995; Cramer *et al.*, 2000). Fuelled by a rise in the consumer movement and by the growing importance of giving individuals and their families a voice in treatment decisions, QoL assessments that incorporate these perspectives have gained a place in the processes of quality assurance and the difficult task of improving services for persons with schizophrenia (Llewellyn-Thomas, Sutherland and Tibshirani, 1982; Levine, 1987; Ellwood, 1988; Geigle and Jones, 1990; Lehman and Burns, 1990; Struening *et al.*, 2001).

QUALITY OF LIFE AS AN OUTCOME MEASURE IN MENTAL HEALTH

In the wake of deinstitutionalisation, clinicians working in the community began questioning the value of such traditional, common outcome measures as hospital readmission rates and symptoms (Schmidt *et al.*, 1977; Lamb, 1979), seeing these hallowed measures as inadequate and simplistic. Hospital readmission, for example, may reveal more about the mental health system and economic conditions than about the clinical status of the person evaluated. Many admissions are precipitated by a concrete need, such as housing, that has little relation to the person's illness. The same individual who is hospitalised in one treatment system might be treated as an out-patient in another, where effective community-based crisis services can meet their needs (Stein, Diamond and Factor, 1990).

Likewise, positive symptoms of psychosis, such as delusions, hallucinations and cognitive disorganisation, were another traditional measure of severity of illness, and change in these symptoms has frequently been used as the primary indication of improvement (Revicki and Maranda, 1994). While reliance on symptoms appeals to common sense, they are actually important only as markers for the severity of the underlying disease process, or if they directly interfere with the person's life. The primacy of symptom outcomes is being questioned in the light of research which shows that symptoms can have a relatively low correlation with ability to function, satisfaction with treatment or self-reported QoL (Anthony and Rogers, 1995; Sainfort, Becker and Diamond, 1996). Symptoms may indicate little about treatment outcome from the consumer's point of viewpoint. Furthermore, because symptoms are an unreliable predictor of function, they can be a misleading outcome indicator. Two people whose symptoms suggest a similarly severe illness may actually have quite different capacities to function in the community and different perspectives on the value of their treatment.

The main advantage of symptoms as an outcome measure is that they can be measured easily and with reasonable reliability (Patrick and Erickson, 1993; Revicki and Maranda, 1994; Fitzpatrick *et al.*, 2001). Without a practical alternative, symptom measures continue as the primary tool for assessing improvement. A published review of therapeutic responses in schizophrenia found that most clinical trials evaluated psychopathology and positive symptoms (Collins, Hogan and Himansu, 1991). Recent studies have expanded their outcome focus to include negative symptoms, but the family or individual's perspective about their experience of the disease or the outcome of treatment is not routinely collected (Lefley, 1990, 1996; Kuck *et al.*, 1992; Siris, 2000). As QoL gains importance as a focus of treatment and outcome research, the development of instruments to measure changes in this area easily and reliably gains urgency (Feinstein, 1992; Lehman, 1992; Patrick, 1992; Gill and Feinstein, 1994; Becker and

Diamond, 2000). The publication of several large clinical trials showing that QoL measures are respon-sive to important changes has further encouraged their use (Wilson and Cleary, 1995).

The emphasis on using QoL (especially as perceived by consumers themselves) as a goal of treatment has gained support from the consumer movement. Indeed, modern treatment of mental disorders gives increased weight to the values and goals of consumers and their families, since all of us have the right to set, as much as possible, the direction and goals for our lives (McCabe and Unzicker, 1995; Leff, 1997). There is also a growing belief that involving people in their treatment produces better outcomes. Meas-uring an individual's subjective evaluation of various life domains is one approach to assessing how mental health services are meeting their needs (Becker, Diamond and Sainfort, 1994).

Concern for the welfare of psychiatric patients in the community has also enlivened the debate over defining and measuring treatment effectiveness (Rosenfield and Neese-Todd, 1993). This concern has challenged professionals to learn to measure QoL accurately in schizophrenia and tease out factors and remedies associated with an improved quality for persons who suffer with mental illness or other perceived disabilities (Edwards, Patrick and Topolski, 2003). Doubtless, future research on QoL both as a concept and an indicator of outcome will fundamentally change policies and programmes from governmental perspectives. Quality of life concerns slowly replaced deinstitutionalisation and community adjustment as the mental health issue of the 1990s (Schalock *et al*, 1989).

CHALLENGES TO DEFINITION OF QUALITY OF LIFE

Defining and measuring QoL in the context of schizophrenia is extremely complex. Disagreements about its definition abound, despite a growing body of research (Mor and Guadogoli, 1988; Deyo, 1991; Spilker, 1992; McHorney, 1997; Garratt *et al*., 2002). As noted by Gill and Feinstein (1994), 'Despite the proliferation of instruments and the burgeoning theoretical literature devoted to the measurement of quality of life, no unified approach has yet been devised for its measurement, and little agreement has been attained on what it means' (page 619). Although the field lacks a consistent definition and measurement approach, consistent trends, ideas and propositions unite the diversity of opinion about QoL measurement. For example, there is general agreement about the essentially subjective nature of QoL and an emerging consensus regarding its major component domains (Bergner, 1985, 1989; Diener *et al*., 1999; Spilker, 1990).

Most definitions consider: (a) physical health status, (b) functional ability, (c) psychological status and well-being, (d) social interactions and (e) economic status (Spilker, 1990). QoL instruments used in mental health generally include one or more of these domains, often using Lehman's structured interview as the model for collecting data. However, there is little discussion, let alone agreement in the literature, about a standard rule for criteria as to which domains are essential for assessing validly a clinical programme or a person's improvement with treatment. These limitations extend to the problem of weighting and scoring domains, which has been done only arbitrarily. This lack of conceptual clarity, as well as the absence of standardisation, have exacerbated the problem of developing useful instruments, preventing generalisation between studies, and so adding to conceptual confusion and ethical concerns (Mor and Guadogoli, 1988; Guyatt *et al*., 1989; Mike, 1992; McHorney, 1997).

METHODS OF MEASUREMENT

While there are currently no agreed standards for defining or measuring QoL for persons with schizo-phrenia, many instruments and scoring methods have been developed. For example, Van Dam, Somers and Van Beek-Couzijn (1981) estimated that more than 250 methods had been used to assess QoL in medicine; in 1990, Spilker and colleagues reviewed more than 300 QoL indices, with a diversity of meas-urement strategies and scaling approaches, ranging from disease-specific to generic. Existing instruments cover an array of domains, use several methods of aggregation and ascribe various 'weights' to different items and domains (Deyo, 1991; Berzon *et al*., 1995; Delespaul, 1995). A diversity of QoL instruments and measurement methods have been developed for schizophrenia (see, for example, Becker, Diamond and Sainfort, 1993; Bigelow, McFarland and Olson, 1991; Heinrichs, Hanlon and Carpenter, 1984; Lehman,

1996; Cramer *et al.*, 2000). Many of these instruments and measurement methods have limitations in their general strategy and application. Disagreement about measuring methods in schizophrenia are generally attributed to differing views about the importance of preferences and varying goals, the goals of researchers and clinicians, and different views of the appropriate roles of consumers and their families (Baker and Intagliata, 1982; Becker, 1995; Cramer *et al.*, 2001).

Much discussion has focused on the role of self-report questionnaires and individual preferences in evaluating and scoring QoL data (Pickney, Gerber and Lafave, 1991; Pavot and Deiner, 1993; Thepa and Rowland, 1995; Atkinson, Zibin and Chuang, 1997). It is well known that subjective and objective assessments of QoL domains do not necessarily coincide, further complicating the measurement process (Heady, Veenhoven and Wearing, 1991; Rosen, Simon and Mckinsey, 1995; Diener *et al.*, 1999). Furthermore, some studies show that biological and psychosocial factors influence each other and that measures of subjective QoL are affected by the clinical status of the individual (Lehman, 1992; Becker, Diamond and Sainfort, 1994; Mechanic *et al.*, 1994; Diener, 1996; Becker, 2003). Although a few studies have looked at the correlations between distinct domains of QoL, researchers have not studied their interaction, and there is little information about how outcomes in different domains are related to treatments received.

Nevertheless, the importance of consumers' perceptions is underscored by evidence that individuals' perceptions of their QoL (which include how they see their own health) reliably predict loss of function, morbidity, mortality and functioning in physical, psychological and social terms (Gill and Feinstein, 1994; Smith, Avis and Assmann, 1999). The interrelatedness of different aspects of peoples' lives is illustrated by data showing that both psychopathology and environmental factors affect QoL; however, the exact nature of the interaction is undetermined (Meltzer *et al.*, 1990; Lehman, 1992; Becker, Diamond and Sainfort, 1994; Ryff and Keyes, 1995). While an outside observer can verify objective aspects independently, this is not possible for subjective assessments.

Until the complex relationship between subjective and objective dimensions of QoL are better understood, global assessment of it will not be a useful or sufficient outcome measure for clinical trials or for evaluating mental health services. New reliable instruments must be developed to measure individual perceptions and specific elements that affect QoL in schizophrenia, so that important interactions between objective and subjective factors can be studied. While several conceptual models for relationships among domains of QoL have been proposed, these models often exclude domains identified as important to consumers and their families. Typically, such proposed models have not been empirically tested (Wilson and Cleary, 1995). The chief goal of existing studies has been that of describing and measuring QoL outcomes in clinical trials and programme evaluation. Relatively unstudied are the relationships between QoL and other outcome measures, and the correlations between separate domains in global QoL. In the short run, rather than limit domains by standard definitional inclusion or exclusion criteria, we might do well to view QoL as a causal network of interrelated domains that require further study so as to determine the entities that determine this multidimensional construct.

SELECTING AN INSTRUMENT FOR MENTAL HEALTH SETTINGS

To be useful, an instrument for measuring QoL in schizophrenia must be appropriate for the setting and reflect the aims of the researcher or practitioner using it. Any instrument designed for use in a (typically overburdened) mental health treatment setting must be fast to administer and easy to understand and score. Its questions must fit categories that both consumers and clinicians feel are important. Since clinical charts are often incomplete, disorganised or illegible, in order to minimise the clinician's time investment the instrument must seek a minimum of information from there or elsewhere. All information sought must be directly relevant to the clinical work. Consumers and staff will willingly complete an instrument only if the information is relevant and useful to both. Ideally, the information will also be directly useful to planning, implementation and evaluation of care as well.

Along with Feinstein (1992), we believe that in clinical practice the most important domains of QoL are those that the consumer wants to improve in the clinical setting. An appropriate instrument would also consider the unique characteristics of the illness and what problems might be encountered in data collection. Assessment can be complicated by problems associated with decreased attention span,

cognition, energy and mood. Additionally, poor communication ability and reality testing may present obstacles to assessment, as can limited educational background.

The mental health field is witnessing an ongoing debate about the value of self-report and interview methods for measurement of QoL (Atkinson, Zibin and Chuang, 1997). Because of an untested assumption that persons with schizophrenia cannot reliably complete paper-and-pencil self-report questionnaires, most investigators have developed interview administered questionnaires, which are expensive. This practice has limited the use of QoL as a routine measure for use in clinical practice. There is, however, growing empirical support for using shorter, self-administered instruments. Self-report paper-and-pencil QoL instruments for mental health have passed internal consistency and test–retest reliability standards (Revicki and Maranda, 1994; Becker, 1995).

Data suggest that a brief, self-administered QoL measure can yield results consistent with in-depth interviews (Greenley and Greenberg, 1994). Furthermore, evidence from research with physically ill persons suggests that self-administered instruments might suffer less contamination from social desirability concerns, which are stronger in interviews. In some studies, self-administered questionnaires have shown a lower subjective QoL rating than interviews (Bremer and McCauley, 1986). Because people may be more honest about their feelings without the pressures of the face-to-face interview, self-administered assessments of QoL could be more valid than interview assessments. Finally, self-report data collection is cost-effective. Research shows that personal interviews cost 3 to 10 times as much as self-report paper-and-pencil approaches (Anderson, Bush and Berry, 1986).

NEW DIRECTIONS IN QUALITY OF LIFE MEASUREMENT

In the United States, there have been enormous changes in recent decades in the organisation financing and culture of the mental health delivery system and in the roles of its participants (Mechanic 1991, 1997; Fischer, Shumway and Owen, 2002; Ridgley et al., 2002). For example, the psychiatric professional's relationship has moved away from one characterised by paternalism to another in which consumers take an active role in their care and are more fully engaged in self-management of their illness (Eckman et al., 1992; Smith et al., 1997; Tauber, Wallace and Lecomte, 2000). Along with the development of consumer-run services and a shift towards their increasing autonomy and responsibility has come a rising demand for a more participatory approach to outcome measurement and psychiatric research. A confluence of forces, including changes in the focus of disability policy from dependence to independence, the growing strength of the consumer movement and emphasis on self-management, has raised professionals' awareness of the importance of participation of consumers and families in both health care and research. These events have sparked a demand for the incorporation of consumer preferences in health care decision making and the development of new, more consumer-centred approaches to QoL and other measurements of outcome. The Wisconsin Quality of Life Index W-QLI (Becker, Diamond and Sainfort, 1993) exemplifies this new approach to measurement.

Development of the W-QLI, initially called the Quality of Life Index for Mental Health (QLI-MH), began in 1991 when a state Medicaid agency approached Becker to help with a cost–benefit assessment for clozapine, a new and very expensive antipsychotic. The agency wanted to develop authorisation criteria and assess which individuals showed enough improvement with the drug to justify its continued use at the high cost. It quickly became apparent that there was no easy way to assess 'improvement' in a largely community-based sample of individuals throughout the state. A significant number of people did not seem improved, based on their change scores for the required Brief Psychiatric Rating Scale (BPRS), yet they were reported by treating clinicians as improved enough to warrant staying on clozapine, despite its high cost, risks and need for weekly blood tests. An outcome measure was required that would capture the complexity of 'improvement' from the perspectives of the consumer, clinician and later the family. It was also important to consider the complexity of change: one person may have significant improvement in one area, while someone else might improve very differently. A consensus developed that QoL, with all its complexity, was the best outcome for measuring meaningful change in persons with treatment-resistant schizophrenia.

Since the literature at that time did not reveal an instrument that would be easy to use, capture client values and preferences, and include provider, client and family perspectives, we undertook to develop a new

instrument. Our approach was influenced by a desire for a practical measure that clinicians would willingly use, and that would encompass what both clinicians and consumers considered most important in their common-sense notion of 'improvement'. The final definition for QoL was influenced by many other definitions, including the work of Andrews and Withey (1976), Campbell, Converse and Rogers (1976) and Ferrans and Powers (1992). Along with Ferrans (1990), we defined QoL as 'a person's sense of well-being that stems from satisfaction or dissatisfaction with the areas of life that are important to him/her'. Since, according to this definition, QoL is determined by the patient's values and perceptions of what is important, it followed that the instrument would have to allow for individual preference weighting.

Decisions on scoring are an integral part of instrument development. For example, there is no obvious way to decide whether the domain of health status is more or less important than that of interpersonal relationships. Allowing multiple responders to rate the importance of different areas allows investigators to analyse whether the consumer, clinician and family agree on the relative importance of different areas of the consumer's life. Developing the new instrument was complicated by the complexity of the construct and by the number of possible methods of aggregation and scoring of each domain. The most common scoring approach has been the multifaceted one, which provides a global score for QoL by aggregating across items and domains. However, this would lose important information about specific domains that: (a) decrease the clinical utility of the instrument and (b) limit information about causation, which operate on specific outcomes, not on aggregations of domains. Thus, in the W-QLI, we decided to score and analyse the different QoL domains separately, so that the outcome of each domain could be evaluated and the causal processes for both negative and positive outcomes could be studied.

While aggregated or single-score measures of QoL may be useful for economic decision making, they are not very helpful for clinical work. The objectives of improving clinical practice and QoL outcomes requires discrete knowledge of the impact of treatment on specific domains and of the processes which bring about that improvement. Domain-specific information allows clinicians and researchers to better understand the process by which individuals judge their overall QoL, and how different domains are perceived and valued. Such data help to discriminate between the long-term effects of competing therapies and can be used in making resource-allocation decisions and treatment planning.

The conceptual framework for the W-QLI included eight semi-independent domains: life satisfaction, occupational activities, psychological well-being, physical health, social relations, economics, activities of daily living and symptoms. Each is independently assessed by the consumer, the primary clinician and a family member (if available). Goal attainment is included as a ninth domain, with its own scoring strategy (see Fig. 10.1). The instrument represents a new approach to measurement, which is inclusive
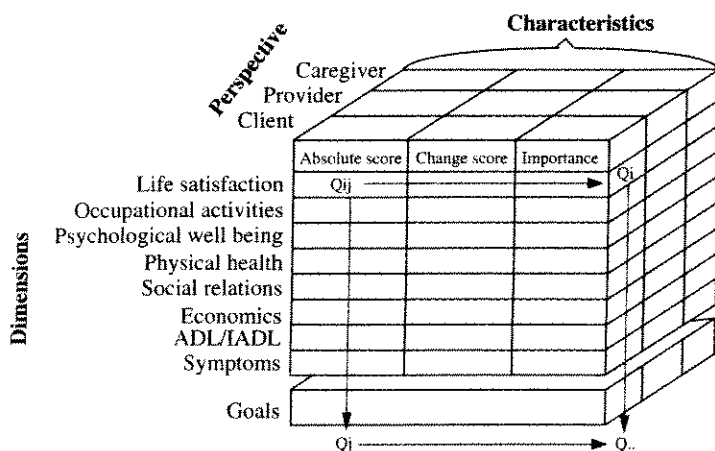
Qij = Evaluation of a particular dimension with respect to a particular characteristic.
Qi = Evaluation of dimension across characteristics.
Qj = Evaluation across dimensions.
Q.. = Evaluation of quality of life as a whole (perceived QoL)

Figure 10.1 Wisconsin Quality of Life Index, a multidimensional conceptual model for evaluating quality of life

of both the consumer and the family. Although intended for people with schizophrenia, it can be used for other community-dwelling individuals with severe and prolonged mental disorders.

MULTIDIMENSIONALITY OF THE CONSTRUCT

In developing the Wisconsin Quality of Life Index, we conceptualised QoL as a complex, multidimensional construct that includes subjective or perceived (consumer-rated) as well as objective assessment of each domain. In this conceptual model, the greater the discrepancy between what is desired and what is achieved, the poorer the outcome. Thus, QoL is a reflection of how patients perceive and react to important aspects of their lives, including both their health status and important aspects of non-medical status. An individually preference-weighted measure is assumed to be more accurate in reflecting consumer values. If, as suggested by Diamond (1985) and others, consumers' subjective experiences influence the phases, course and outcome of schizophrenia, then it is particularly important that QoL measurements reflect their points of view (Strauss, 1989, Weiden, Dixon and Frances, 1991; Awad, 1993, 1994, 1995).

Since the W-QLI domains are all facets of a person's underlying QoL, moderate correlations were found between and among them. However, the observed correlations between domain scores were not strong enough to raise the possibility that the domains were not empirically distinct from one another. For example, in keeping with clinician descriptions, we found that activity of daily living (ADL) functioning was only weakly associated (0.33) with psychiatric symptoms. Our data show that patients with similar levels of ADL functioning can experience mild or severe psychiatric symptoms. Psychiatric symptoms and consumers' global ratings of their life quality were only modestly correlated, suggesting that perceived QoL is not well predicted by psychopathology. In our validation study of the W-QLI, the domain most strongly correlated with global QoL was social relations (0.58).

ISSUES OF SENSITIVITY

Although most QoL measures give equal weight to the separate domains assessed, it is unlikely that each domain would have the same significance to persons of different ages, genders and ethnicities. Despite concern expressed about the cultural sensitivity of QoL instruments, few have attempted to validate existing measures with diverse populations. Since subjective assessment of QoL is inherently based on one's values, attitudes and conceptual framework, it is very likely that significant differences in culture will affect the measurements. Despite the current emphasis on cultural sensitivity, consumer values, empowerment and choice in mental health, few of the commonly used instruments allow responders to evaluate separately the importance of different domains or to add information about their desired goals for improvement with treatment.

It is very likely that different cultural groups will weight the domains differently. Unfortunately, initial data from the W-QLI did not include enough culturally diverse subjects to analyse this issue, though preliminary data suggest that men and women with schizophrenia use different importance weightings. These observed gender differences are in the same direction as would be expected in the general population. For example, women rank interpersonal relationships as more important to their QoL than men, while men rank the importance of occupational activities higher than women (Becker, Diamond and Sainfort, 1994). As anticipated, we found differences between clinicians and consumers in their weighting of domains: clinicians placed more importance on symptoms, while consumers rated social relations as more important.

GOAL ATTAINMENT AS PART OF A QUALITY OF LIFE MEASUREMENT

If, as has been suggested by Ryff (1995), QoL is 'in the eyes of the beholder,' then measurement of it must be based on the individual's evaluation of the distance to the desired quality and on personal goals for improvement with treatment. Surprisingly, despite ample evidence about the importance of

consumers' preferences and goals to QoL assessment, existing measures rarely ask about goals or the degree to which consumers believe these are being achieved. While one person may stress ability to work as a primary goal of treatment, another may stress the absence of medication side-effects or improved personal relationships. Goal attainment information can have many uses in psychiatry. Diamond (1985) and others have argued that attention to personal goals, along with the subjective effects of medication, can positively affect adherence to prescribed medication and thus influence treatment outcomes (Weiden, Dixon and Frances, 1991; Awad *et al.*, 1995; Awad and Voruganti, 1999). Attention to an individual's desired goals for improvement can also help in planning rehabilitation approaches and can inform decisions on vocational or residential placements (Anthony, Cohen and Marianne, 1990). The Wisconsin Index asks individuals to state their goals for improvement with treatment, as well as ranking the importance of the goals and the degree to which they feel they have achieved them. Documenting a person's important goals and unmet needs may help clinicians to improve their clinical practice by targeting interventions to the areas of greatest need. Information from the W-QLI goals domain can be used to create a matrix of client needs; it also allows consumers and staff to track progress towards goals that have been selected as most important.

A taxonomy of the goals for improvement with treatment, as proposed by clients, clinicians and families, was developed by Becker and Feinstein (1994) from the verbatim data provided by the W-QLI (Table 10.1). The outline of categories proposed by responders indicates that clients desire the very things that make up a good QoL. The dimensions of the taxonomy of responders' goals for improvement with treatment bear a striking resemblance to the conceptual model of QoL that was used to develop the W-QLI and to the dimensions identified by a factor analytical study of W-QLI data. The results of the factor analysis, based on data from 397 persons with schizophrenia, indicate that the underlying factor structure of the W-QLI is composed of three core constructs: (a) perceived life satisfaction (alpha = 0.83), (b) psychological symptoms/outlook (alpha = 0.80) and (c) social relations (alpha = 0.68) (Becker, Thorton and Banks, 2000). Both these findings and our experience with this measure argue that QoL for persons with schizophrenia is a multidimensional construct that can be measured quantitatively with a self-administered questionnaire. Most but not all persons can complete the paper-and-pencil form with a minimum of difficulty, though some require the help of a peer coach or professional interviewer and a few may be too ill to respond sensibly. These findings support the sensibility of a conceptual approach to QoL measurement that incorporates the individual's perspective instead of imposing a socially prescriptive definition. Preliminary data collected with the W-QLI

Table 10.1   Outline of categories: taxonomy of treatment goals for improvement of persons with schizophrenia proposed by clients, clinicians and families

1. *Control of disease*
    1.1 Manifestation of illness
    1.2 Therapy
    1.3 Side-effects of therapy
    1.4 Co-morbidity

2. *Personal status*
    2.1 Self-care
    2.2 Independence
    2.3 Sense of well-being

3. *Interpersonal status*
    3.1 Family relationships
    3.2 Non-family relationships
    3.3 Social functioning

4. *Care giver relief*
    4.1 Less dependence on parent
    4.2 Less dependence on spouse
    4.3 Less dependence on professional staff

5. *Miscellaneous treatment goals*
    5.1 Main hope for the future

indicate that both families and consumers more frequently stress the importance of goals related to desires for improved social relations and interpersonal functioning, while clinicians more frequently stress goals related to symptom reduction and compliance with treatment.

DIRECTIONS FOR FUTURE RESEARCH

Despite extensive investigation in medicine, we still know relatively little about the causal sequence of quality of life or the important interaction between objective and subjective factors in it. The situation is further complicated by empirical evidence showing that positive QoL evaluations represent different causal processes from negative evaluations (Heady and Wearing, 1989) and that subjective and objective evaluations do not necessarily coincide. For example, depending on the study, an individual's mood can account for up to 40% of the variance in QoL outcomes (Moum, 1988; Becker, Diamond and Sainfort, 1994). While it is clear that QoL is not independent of morbidity, the exact nature of the connection is unclear (Smith, Avis and Assmann, 1999). Since research has not examined the interaction of symptoms with occupational and functional outcomes in schizophrenia over time, we remain uncertain about the relative importance of these factors to the course and outcome of the disease. Although many of the studies dealing with chronic mental illness have focused on schizophrenia, they have mostly considered psychopathology and have been focused on positive and negative symptoms, rather than on functional or subjective outcomes (PogueGeile and Harrow, 1984; Lehman and Burns, 1990; Fenton and McGlashan, 1991). Thus, additional research is needed on the relationships between relevant domains, but until the necessary theoretical work is accomplished, definitional confusion is likely to remain.

Additional research is also needed to validate the applicability of the numerous measures to diverse social–cultural groups and across the developmental and chronological age span. Further, we need studies to understand the psychological reaction of patients to their illness and to examine QoL as several different causal sequences, rather than a single outcome. Comparative studies should determine which instruments or combination of instruments and measurement approaches are most useful, reliable and valid for measuring QoL in persons with schizophrenia.

To understand the complex dynamics of QoL in schizophrenia, the interrelationships of important factors such as coping style, mood, hopefulness and economic–employment status need further study. These factors have been shown to have an importance influence on QoL (Evans, 1981, 1991; Moum, 1988; Jenkins et al., 1990; Farran, Herth and Popovich, 1994). For example, one possible way of coping with schizophrenia is for people to reduce substantially their goals and expectations. However, while an avoidant style of coping may reduce negative QoL, it also reduces positive events and therefore may reduce life quality. We propose that future research should concentrate on investigating the causal sequence of QoL and important interactions between psychiatric morbidity and other quality factors. Future studies with the W-QLI will include investigations of the links and interactions between separate domains, goal attainment and the importance of culture, gender, economics and treatment setting to QoL outcomes in schizophrenia.

CONCLUSION

Results from the validation studies of instruments that document QoL measures can be sensitive to population differences and treatment effects (Malm, May and Dencher, 1981; Levitt, Hogan and Bocosky, 1990; Bigelow, McFarland and Olson, 1991; Lehman, Slaughter and Myers, 1991; Revicki et al., 1992; Lehman, 1996, 1997; Becker, Martin and Thornton, 2001). Hence, they can be used to evaluate the effect of drug therapy and to measure the cost /benefits of the mental health service (Hogan, Awad and Eastwood, 1983; Patrick, 1992; Revicki and Maranda, 1994). However, due to the variety of definitions and approaches used in existing research, interpreting and generalising from it is difficult.

It is premature to make recommendations about specific instruments or to generalise from initial results. Our challenge now is to develop consistent definitions, scoring and concepts. Use of a standardised approach and instruments would allow meta-analysis of divergent studies and so increase our understanding of QoL as a treatment outcome and causal sequence in schizophrenia. To ensure that

instruments are measuring what is important, we need to develop a comprehensive and coherent theoretical model to inform the research methodology, to guide the construction of new instruments and clinical practices, and to improve the life quality of people who are being treated and living in the community. Finally, every effort must be made to incorporate consumers' and families' points of view in QoL assessment. Additionally, researchers need to create a forum to bring innovations in this research into the mainstream of professional dialogue.

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