

Measuring quality of life in the mentally ill

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Abstract

It has been our experience that it is easier to measure quality of life among persons with serious mental illness than it is to intervene to improve it. This article presents background and historical context of service delivery to persons with severe mental illness. We then examine approaches to assessing outcomes of services, especially quality of life. We conclude with an illustration and discussion of dilemmas in measuring quality of life in this vulnerable population.

Background

We define serious mental illness (SMI) in terms of disorders and disabilities. For example, PL 102-321 [1] defines SMI as the presence of a mental disorder (as defined in the Diagnostic and Statistical Manual of Mental Disorders – DSM IV) [2] that leads to disability understood as ‘substantial interference’ with ‘one or more major life activities.’ Typically the disorders that are considered are schizophrenia, mood disorders, including major depression, and other severe conditions including schizoaffective disorders and, increasingly, severe personality disorders. Indicators of disability resulting from mental illness include history of psychiatric treatment more intensive than outpatient (e.g., multiple inpatient, residential), impaired role functioning (especially in relation to employment), problems with establishing and maintaining support systems, and need for help in basic living skills. Many people with SMI are not able to work. The age of onset of most SMI, especially schizophrenia, is in the late teens and early 20’s. Therefore, the disability usually may mean a lifetime of disability, with no history of work prior to the illness. This situation also makes the illness par-

ticularly difficult for individuals and their families – to see illness and disability at an age when most people are going out to work and form relationships. Instead, persons with mental illness need assistance with relationships and often need help in basic living skills.

Why is it important to focus on SMI? Severe mental illness has an impact on both individuals and on our society. Over 5,000,000 Americans (2.8% of the population) will develop severe mental disorders. Direct costs of mental illness are enormous – \$20 billion. Twenty-five percent of all federal disability payments (supplement security income, SSI and SSDI) go to persons with severe mental disorders [3]. Indirect costs from family caregiving and lost wages and productivity are nearly four times the direct costs – \$74 billion. In addition, this group often has high rates of comorbidity with substance abuse. Kessler et al. [4], in their epidemiological study, found that 79% of lifetime disorders were comorbid disorders.

Historical context

Warehousing of the mentally ill was a major problem which continued until relatively recently.

There have been a number of crusaders for more human treatment, such as Dorothea Dix who, in the 18th century, traveled throughout the eastern United States doing what we might call today investigative journalism in jails and poorhouses, looking at how people were chained and mistreated. Dix presented her testimonials about the bad conditions for the mentally ill to state legislatures. Often she was not allowed to enter the legislative chambers because she was a female. By presenting testimonials, she hoped that legislators would appropriate funds for the building of asylums to improve the treatment of the mentally ill. Over a century later, exposés again revealed deplorable living conditions for the mentally ill, but now they were in state hospitals. Vivid pictures appeared in popular magazines and fictional accounts such as *One Flew Over the Cuckoo's Nest* [5] led to public support for addressing the problem. Coupled with humanitarian concerns in the civil rights movement from the 1960's to 1970's, we began to see forces coming together to change the hospitals and return the mentally ill to the community.

Certainly one of the factors leading to deinstitutionalization was the development in the 1950's of more effective psychotropic medication which made it possible to manage the illness without prolonged, sometimes life long, hospitalization. Another significant factor was the ability of states and counties (that supported the state mental hospitals) to transfer the cost to the federal government as Medicare and Medicaid became available for care in nursing homes. However, deinstitutionalization brought with it not successes at first, but often failures. The first failure discovered was that relapse rates were high. We began to describe hospitals as having 'revolving doors.' People would be released, without help for their caregivers, after a short hospital stay, given an appointment to see the doctor to get their medications, they would not make their appointment and would end up back in the hospital. That was the outpatient model that we thought would work, but it did not.

Another reason for failure of the post deinstitutionalization outpatient system was low rates of medication compliance. By the early 1980's we knew that inadequate outpatient care and poor compliance had contributed substantially to the

increase in homelessness in this country. At that point probably about one third of the homeless were persons with severe mental disorders. Although a number of programs have been introduced which have been shown to reduce homelessness among persons with SMI e.g., [6], we are now seeing an increase in the number of mentally ill persons in prisons and jails.

Current practice

Researchers have been looking at the extent to which persons with chronic mental illness have access to known effective treatments [7]. While the figures on access to medications are relatively good, the figures on access to psychosocial interventions known to be effective are quite poor. Less than 10–20% of persons with severe mental illness have access to either assertive community treatment or psychoeducational treatment, the two known effective psychosocial interventions. We continue to have low rates of employment among this group, and most people continue to depend on SSI for basic living expenses (average \$ 545/month [8]), accounting for the poor quality of housing available to this population, especially in urban neighborhoods.

Measuring outcomes of services to persons with SMI

The focus on program evaluation and outcome assessment dates to mandates of the federal community mental health center (CMHC) legislation. The 1975 amendments (PL 94-63) required CMHCs to spend 2% of their budget on evaluation. Frameworks to guide evaluation date to this period (e.g., [9]). Their framework focused on the client level, including four domains: symptoms, level of functioning, satisfaction with services, and quality of life. (Interestingly, some of the quality of life measures that are introduced now actually cover all of those domains – see below.) It is also possible to look at program and system level outcomes, although these are processes as well as outcomes. Indicators of system level outcomes include access to known effective treatments and system integration.

As in most fields, when measuring quality of life we look at both subjective and objective dimensions. Subjective domains include: well-being, satisfaction, and happiness. Subjective assessments may also be made of objective domains, for example, satisfaction with housing. Objective domains typically include housing, neighborhood safety, access to grocery stores and funds for access to leisure activities. Exposure to violence and trauma should be included when assessing neighborhood safety and the safety of the immediate interpersonal environment.

Quality of life instruments for persons with mental illness may be considered as related to but different from other measures of general well being, for example the Medical Outcomes Study instrument, the SF-36 [10]. These tools generally obtain an assessment of a client's perception of general well-being, but rarely delve into perception of domains such as housing, neighborhood, etc.

Existing instruments also differ in terms of how information is obtained. For example, some instruments are completed through client self-report. Others are conducted by trained interviewers. Still others involve assessment by an outside rater – especially those that attempt to assess objective domains.

In 1997 van Nieuwenhuizen et al. [11] reviewed eleven instruments for measuring quality of life for persons with severe mental illness. Of the eleven, three did not have data available about reliability and validity. Eight involved structured or semi-structured interviews; three were self-report measures. Only two included some observations of, or assessment of, objective conditions by others. The instruments covered between four and 18 domains, although one reported only a single global domain. The most commonly assessed domains are: employment/work, health, leisure, living situation, and relationships. (See Table 1. It includes the above 11 instruments and the three below.)

Three additional instruments for measuring quality of life among the SMI have been published since the 1997 review. Greenley, Greenberg, and Brown [12] developed a 24-item self-report measure with good psychometric properties. Factor analytic studies confirmed a seven-factor structure covering the following domains: living situation, finances, leisure, family, social life, health, and access to medical care. Dazord et al. [13] report on

the development of a French 36-item self-report instrument. It has good reliability. Some aspects of validity were tested, but no factor analysis was done in the development of the dimensions/domains assessed. Katsavdakakis et al. [14] have developed a 55-item scale that emphasizes the consumer's perspective, both in use of language, form of administration (dialogue with the consumer), and in selection of domains relevant to consumers. It is designed for use repeatedly during clinical practice as part of a general approach of involving consumers in assessment of progress and outcomes. Preliminary studies indicate promising psychometric properties.

Concerns about existing QoL instruments for persons with SMI

A variety of concerns and criticisms have been raised about existing instruments. Some of these are concerns regarding all quality of life measures; some are specific to use of these measures with persons with SMI. General concerns include: conceptual issues, psychometrics, utility, and range of domains assessed. Gladis et al. [15] address conceptual issues, noting the lack of 'a taxonomy of quality of life instruments based on theory' (p. 321). They find two dominant models emerging, a generic satisfaction model and a three component model. The satisfaction model emphasizes fulfillment of aspirations. However, it has been criticized for excluding functioning and social-material conditions. The three component model includes all of these.

Not all of the instruments currently available have had adequate tests of reliability and validity. Few have had appropriate factor analytic studies of the items to determine domains assessed. Discriminant validity continues to need to be addressed, especially because some instruments include symptom dimensions. Clearly, psychometrics should be considered when selecting instruments for use in research or practice settings. The major concerns about utility center on the length of the instrument and the extent of training that raters need if it is not a self-report measure.

Some relevant domains are not included in most instruments. Only one of the measures reviewed

Table 1. Assessment domains: quality of life measures for SMI

Instrument domains	Instruments													
	1	2	3	4	5	6	7	8	9	10	11	12	13	14
Ability to cope							X							
Ability to go out													X	
Activities of daily living											X		X	X
Basic need satisfaction			X											
Clothing		X												
Common objects and activities					X									
Concentration													X	
Contacts										X				
Dependency	X									X				
Digestion													X	
Economic situation		X									X			
Employability			X											
Employment/work	X			X		X	X	X		X	X			
Environment										X				
Everyday movements													X	
Family and children						X								
Feelings														X
Finances			X	X		X	X	X				X	X	
Food		X											X	
Friends		X				X								
Friends and community							X							
Goal attainment											X			
Health		X	X	X		X		X		X	X	X	X	X
Housing	X	X								X				
Independence			X											
Inner experience	X									X			X	
Instrumental role					X									
Interpersonal relations			X		X									
Intrapsychic foundation					X									
Knowledge and education	X						X	X		X				
Legal								X						
Leisure	X	X	X	X		X	X	X		X		X	X	
Living situation		X		X		X	X	X				X		X
Material possessions													X	
Meals													X	
Medical care section	X											X		
Mental health										X	X			
Negative consequences – alcohol			X											
Negative consequences – drugs			X											
Neighborhood		X												
Occupational activities											X			
Overall fitness													X	
Partner and sexuality						X								
Physical appearance													X	
People living with		X												
Psychiatric medications			X											
Psychological distress			X											
Quality of life									X					
Relations with family		X		X			X	X				X		
Relations with others		X												
Relationships/social support	X		X					X			X	X	X	X

Table 1. (Continued)

Instrument domains	Instruments													
	1	2	3	4	5	6	7	8	9	10	11	12	13	14
Religion	X			X				X		X				X
Safety				X				X						
Self and home maintenance			X											
Services and facilities		X												
Sleep													X	
Spouse role			X											
Symptoms											X			
Tolerance of stress			X											
Well-being			X											
Work and day programming		X												
Work at home			X											
Work on the job			X											

above included partner and sexuality as a domain, and only a few considered spirituality or religion. The one that included sexuality is in German. As early as 1917, Mary Richmond, a famous social worker, wrote on social diagnosis using detailed interviews [16]. She included sexuality and sexual behavior in her interviews. Satisfaction with sexuality and sexual expression are important domains in the quality of life of all adults. In addition, because adults with SMI may experience medication side effects which influence sexual expression, and because they are at higher risk of HIV infection, this dimension should be considered.

Two concerns have been raised regarding measurement of QoL among the SMI: influence of the illness on judgment and lowered expectations [17]. Major mental illness impacts both cognitive and affective functioning and may therefore impact client judgments. While illness effects cannot be discounted, they do not mean that we should avoid obtaining reports directly from individuals with SMI. Another concern is that persons with SMI may have lowered expectations about their quality of life, whether that relates to living conditions or other domains. They may give ratings of satisfaction because they have become resigned to their own condition and that of their environment [18]. Lack of insight and lack of motivation may also lead to lowered expectations [19, 20]. Orley et al. [17] argue for emphasizing the clients' views, regardless of the issue of lowered expectations. Others, e.g., [21], based on findings of difference

between subjective assessments and objective indicators, argue for use of both. We argue that lowered expectations necessitate some assessment of objective conditions in addition to self-report of subjective QoL (see Table 1). Orley et al. [17] make their argument within the context of the current emphasis on consumer involvement – that the patient's opinion is important, and professionals should not be the only judges of the importance and effectiveness of what they do. A related argument is that global, subjective ratings, such as those associated with satisfaction models, are independent from value judgments about what constitutes a 'good' quality of life [15]. Also it is possible that diminished expectations in this population may well not only be appropriate, but allow patients a sense of accomplishment and even contribute to survival. Perhaps a new approach that involves consumers in assessing objective quality of life is what is needed [22].

The World Health Organization (WHO) has taken a stance that QoL measures are important as indicators of well-being, and that well-being is an essential component of health. The WHO has also emphasized consumer involvement and subjective assessment – 'individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns' ([17] p. 291). They have also taken the stance that QoL measures should not be disease or disorder specific. The WHO measure covers the following domains, perceived to be relevant to all: physical

health, psychological state, level of independence, social relationships, and relationship to features of the environment [23]. The WHO approach and instrument are likely to become increasingly influential.

An illustration of problems in assessing QoL among the SMI

One of the authors studied violence and trauma in a group of women with SMI [24]. Ford's sample was 55 African American women. She found that clients' perceptions of their illness and its impact on their quality of life likely reflect the problem of lowered expectations. For example, their perception of the disruptions in their lives due to their emotional problems, on their various family, social and work domains, were relatively mild. They have seemingly decided that this is their lot in life. Objective indicators of quality of life give a different picture. For example, only four had full or part time employment; most were on SSI, 30%

Table 2. Reported traumatic events from the posttraumatic stress diagnostic scale

Type of assault	N	(%)
Assault/traumatic event		
Childhood sexual assault	7	12.8
Adult sexual assault	12	21.8
Adult physical assault	6	10.9
Adult both	2	3.6
Fatal acts involving murder	8	14.6
Physical assaults of significant persons	1	1.8
Other traumatic events:		
Accident	4	7.3
Illness	4	7.3
Natural disasters	1	1.8
Other	6	10.9
No reported traumatic events	6	10.9

Table 3. Objective measures of disability-related QoL

Only 4 (7.2%) full or part-time employment
61.8% on SSI
30% had not graduated high school

Table 4. Subjective measure of disability-related QoL

Sheehan disability scores (sub-scale range: 0–15)	M	SD
Perception of disruption due to emotional problems		
• Disruption of family/home life	5.04	3.85
• Disruption of social life	5.33	3.84
• Disruption of work life	4.95	4.01

had not graduated high school. That is, the group was not unhappy with their work life. Most have a variety of diagnoses and a history of substance abuse. Many of these women had experienced severe traumas across their life span, both as children and adults. Eight of the women had people close to them murdered. (See Tables 2–4.) We had originally hoped to ask them about acts of violence that they committed, but it was too difficult to do that because of various confidentiality issues. We do know that at least one woman had killed her husband and that a number of them had witnessed violence.

Conclusion

While instruments for measuring QoL among persons with severe mental illness do exist, few have adequate psychometric properties. Most of these are self-report measures of subjective assessment. Authors disagree over the need for objective indicators of quality of life in this population. In addition, we still must ask if there is any reason to believe that what we do in interventions with this population would in fact improve objective quality of life. For example, one study found no differences in quality of life between clients receiving outreach case management and standard aftercare [25]. Quality of life was not improved for either group.

One of the most difficult problems in improving quality of life in persons with severe mental illness is impoverishment; therefore, the only way to get out of impoverishment is either to raise SSI benefits or to improve access to employment. We can hope in the future that persons with SMI will also have access to education and training that would improve their access to employment and therefore improve their objective conditions.

As you can gather from what we have said, we think that it is going to be very difficult to, in fact, improve objective quality of life in this group of people. Is there any good news? Yes. The newest medications have less obvious or disabling side effects. We think that it is important that people not be physically stigmatized by the medication that they are taking to try to make them better. We have programs like assertive community treatment and psychoeducation for families that have been heavily researched, which do help people avoid relapse. Increasingly, supportive and transitional employment programs have been showing promise. There are many reasons to be optimistic, but the barriers to improving quality of life for persons with severe mental illness remain significant.

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