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Quality of life as an outcome measure in evaluating mental health services: a review of the empirical evidence

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Abstract This paper addresses the question of how well quality of life measures function as valid and sensitive outcome indicators of mental health services. Findings from the major empirical studies of quality of life in the mental health area over the last 15 years are reviewed. The extent to which existing studies provide evidence of the ability of quality of life measures to discriminate the impact of service interventions on the well-being of psychiatric clients is examined. Findings from cross-sectional, comparative, repeated-measures and randomised studies are presented. The available empirical evidence is critically examined and the methodological and theoretical implications of current findings for future work are considered.

Introduction

Over the past 15 years there has been a growing emphasis on quality of life in the mental health literature. The quality of life concept is now clearly recognised as providing an evaluative framework against which to assess the outcomes of care provision and offers a useful means of incorporating the client's perspective into the evaluation process. Quality of life has been defined as having both subjective and objective components. The subjective component is frequently referred to as "well-being" or "life satisfaction", and is usually assessed by means of satisfaction ratings concerning different life areas. The objective component includes aspects of living conditions and social functioning such

as accommodation, employment, leisure and finance and is usually determined by direct questions to the interviewees concerning these different aspects of their lives. Progress in the conceptualisation and measurement of quality of life in the mental health field has resulted in a range of quality of life measures that have been applied as mental health service outcomes. There now exists a corpus of research studies concerned with evaluating the impact of community-based services on the lives of psychiatric clients. Given the increasing use of quality of life measures as evaluation outcomes, it is timely to consider the methodological adequacy of current methods of assessing quality of life when used within the context of service evaluation.

In reviewing the quality of life studies carried out over the last 15 years, it is clear that the majority are cross-sectional in nature or have involved comparisons between groups in different care settings. Relatively few studies have applied experimental or quasi-experimental approaches in evaluating the effectiveness of service changes in improving client outcome. As a result, the sensitivity of quality of life measures in evaluating change has not been directly examined. If quality of life is to function as a useful and valid outcome measure, capable of discriminating the impact of different forms of care delivery, it is critical that the measures can be reliably demonstrated as offering sensitive indicators of the impact of service changes on clients' well-being. In order to accomplish this, prospective longitudinal investigations are required. As pointed out by O'Driscoll (1993) in her review of outcome studies of deinstitutionalisation, the strength of the research design has important implications for the ability of findings to support or refute the validity of current policies. This paper brings together the findings from the main studies that have been carried out over the last 15 years, critically reviewing how the data have been collected and interpreted. As the focus of this paper deals with how well quality of life functions as an outcome measure, the paper is structured according to the

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design of the studies in order that the methodological adequacy of the research design, as well as the measures used, can be considered. With this aim in mind the various studies are grouped according to their research design, presenting details of the samples studied and the quality of life measures used, followed by a methodological critique of the findings. The conclusions that can be drawn from the available evidence are discussed and future research directions are considered.

The studies

The quality of life studies in the mental health area were scanned using CD-ROM Medline and PsycLit under the key words: quality of life, mental health, psychosocial rehabilitation, deinstitutionalisation, life satisfaction, community and social psychiatry, and mental illness. Only articles written in English published over the last 15 years are included in the present selective review. The studies are presented on the basis of their research design under the headings of cross-sectional, comparative, prospective repeated-measures and randomised studies. Table 1 summarises the characteristics and key findings of the main studies, drawing out their similarities and difference in terms of service settings, samples, quality of life measures and results.

Cross-sectional studies

The initial large-scale studies of quality of life were carried out in the United States, within the context of developing community support services for psychiatric clients discharged from hospital. These studies focused mainly on chronic psychiatric populations, were cross-sectional in nature and aimed to establish how chronic psychiatric clients perceive their quality of life and how their perceptions compare with those of the general population. Two such major studies were carried out by Lehman et al. (1982) and Baker and Intagliata (1982), setting the research agenda for subsequent work.

Lehman et al. (1982) conducted a survey of 278 chronic psychiatric clients resident in 30 board-and-care homes in Los Angeles. Using the Lehman Quality of Life Interview (QOLI), the psychometric properties of which have since been well established (Lehman 1988), the study examined both subjective and objective quality of life across eight life domains, together with global quality of life. The study found that despite generally poor living conditions, over half of the residents interviewed reported that they felt "mostly satisfied" or better about their lives in most life areas. The main sources of dissatisfaction were poverty, social isolation, unemployment and victimisation. The board-and-care residents were described as being economi-

cally disadvantaged and socially isolated and reported significantly lower levels of life satisfaction in comparison to a national survey sample, particularly in the areas of family and social relations. Based on these findings, Lehman et al. (1982) pointed to the need for community programmes to address the many social problems affecting the lives of community-based clients. From a methodological point of view, the study has demonstrated the feasibility of assessing the quality of life of a chronic psychiatric population in a reliable manner and has established that psychiatric state does not introduce bias into the overall structure of the quality of life data. Global quality of life was found to be correlated with current levels of depression and anxiety (Lehman 1983) and, apart from marital status, correlations between demographic characteristics and well-being were not found.

High levels of general satisfaction have also been reported by Baker and Intagliata (1982) in a study of the perceived levels of quality of life of 118 chronic psychiatric clients participating in a Community Support System (CSS) programme. Using two brief subjective measures of quality of life, the Affect Balance Scale (Bradburn 1969) and the Satisfaction with Life Domain Scale (SLDS), developed by the researchers, levels of life satisfaction among the CSS clients were compared to those of Campbell's (1981) national survey sample. Baker and Intagliata report that CSS clients were generally less positive about their life experiences than the national sample and were significantly more likely to report negative experiences, e.g. they were more than twice as likely to report feeling lonely, bored and depressed. On the SLDS there was a clustering of responses at the positive end of the scale, with CSS clients reporting greatest satisfaction with living situation and being out of hospital. In contrast, they were least satisfied with their current economic situation, use of leisure time and health. From 20 in-depth interviews carried out with members of the sample, it emerged that CSS clients lead a very restricted life and that some were "socially isolated to an extreme degree" and had unsatisfactory relationships with family and friends. Yet, despite these conditions, very high levels of life satisfaction were reported. This paper raised an important methodological question concerning the interpretation of the high levels of satisfaction, which has since remained unresolved. Baker and Intagliata commented, "There appears to be no way to completely determine whether the high levels of positive feelings represent a sincere evaluation of aspects of the clients' lives and reflect the clients' actual perceptions of the environment or are due to grateful testimonials or other biasing factors. The answer probably lies somewhere in between". (Baker and Intagliata 1982, p. 78).

This discrepancy in the information derived from subjective and objective indices of quality of life has also been highlighted in two later studies by Pinkney et al. (1991) and Sullivan et al. (1991). Pinkney et al.

(1991) assessed the quality of life of 55 long-term psychiatric patients who were discharged from two rehabilitation programmes into the community in Canada. At 1 year after leaving hospital, 64% lived with friends or unrelated others, and 22% lived with family. Using the Clients' Quality of Life Instrument and the Uniform Client Data Instrument (Mulkern and Manderscheid 1989), the psychometric properties of which are not reported, it was found that this group of ex-psychiatric patients had adjusted well to life in the community. The overall effects of the move to the community were positive, i.e. the majority (96%) felt that their lives had improved since leaving hospital. However, the researchers point out that the clients in this study were living below the poverty line and that they were in need of help with their interpersonal and employment skills.

Sullivan et al. (1991), using sections of Lehman's QOLI, interviewed 101 clients with serious mental health problems 13 months after hospital discharge. The findings from this Mississippi sample, 78% of whom were African-American and residing with their family in mainly rural areas, suggested that despite "extreme poverty" and what would objectively be considered a poor quality of life, they reported a relatively high subjective quality of life, particularly in the areas of living situation, health and life in general. More than 66% were satisfied with all life domains except finance and no more than 15% reported being dissatisfied with any of the life domains except finance. While the findings from this study are limited by the fact that objective indicators were not employed in the assessment of quality of life and also by the somewhat unique characteristics of the sample, it would appear that extremely impoverished objective life conditions are not necessarily reflected in life satisfaction ratings. However, social life and finances did emerge as the main sources of dissatisfaction, and this sample was more dissatisfied with these life areas than subjects in the American national sample representing black and lower SES groups.

Shadish et al. (1985) conducted a survey of the subjective well-being of 163 chronic patients in nursing homes, 79 of whom were questioned in detail. The researchers employed seven subjective well-being measures, all of which had been used in previous studies, and one measure of residents' perceptions of the psychosocial environment (Sheltered Care Environment Scale; Moos and Lemke, 1979). Data on three comparison groups were also collected: 19 inpatients, 22 outpatients and 18 nursing home staff. Comparisons were also made with earlier reported findings from general population surveys (Veroff et al. 1981; Bradburn 1969). The nursing home patients, whose average age was 48 years and 59% of whom were female, reported lower levels of well-being than the general population but were not significantly different from other disadvantaged groups in society or psychiatric clients in other settings. Reports of subjective well-being were

found to be unrelated to levels of symptomatology or social integration but were strongly related to residents' perceptions of the quality of the environment. Increased satisfaction and happiness was associated specifically with perceptions that the home was cohesive, was low in conflict, encouraged patient self-expression, placed an emphasis on patient independence and influence, was well-organised and was relatively high in physical comfort.

The importance of the quality of the living environment has been explored further by Skantze et al. (1992). The Standard of Living Questionnaire (SOL-I) and the Quality of Life Self-assessment Inventory (QLS-100), both developed by the researchers, were used to interview 61 Swedish outpatients who suffered from schizophrenia. The authors distinguished the standard of living, which was defined as the objective dimension of how well the basic needs of life are being met, from quality of life, which they defined as the patients' own subjective view of well-being and satisfaction with his/her life. The sample were described as having attained a standard of living similar to the general population in Sweden, with good access to community and health care facilities. This study found no correlation between the standard of living and subjective quality of life in this population, once a minimum standard of living had been reached. The outpatient sample reported mental health, inner experiences, social contacts and work as major sources of dissatisfaction. The authors argue that the findings confirm that a normal standard of living does not in itself generate high quality of life. However, given the characteristics of the sample—they were young (mean age = 35.9 years), highly educated (92% had college education or further training), had a relatively short history of illness and the majority (69%) lived in their own homes—the generalisation of these findings to other mental health clients may be open to question. While the conclusion that "quality of life and standard of living are independent for schizophrenic patients" (p. 799) may well apply to clients who have attained a high standard of living, the extent to which this finding would also apply to those experiencing poor living conditions is not clear.

The findings from the cross-sectional studies show consistently high levels of subjective quality of life among community-based psychiatric clients. Their quality of life appears to be lower than that of the general public, and finance, social relationships and health emerge as consistent sources of dissatisfaction. The majority of studies report that most demographic characteristics show only a modest relationship with the subjective indicators, and the relationship between objective and subjective indicators also appears to be weak. It is, however, noticeable that many of the cross-sectional studies have concentrated on subjective well-being, mostly applying life satisfaction measures, and have not directly employed objective quality of life indicators.

Table 1 Characteristics and findings of the main studies on quality of life (QoL) and mental health services (QOLI Quality of Life Interview, SLDS Satisfaction with Life Domain Scales, SOL-I Standard of Living Questionnaire, QLS-100 Quality of Life Self-assessment Inventory, QLQ Quality of Life Questionnaire, SMI Seriously Mentally Ill)

Investigators	Type of service	n Size	Measures used	Main results
<i>Cross-sectional studies</i>				
Lehman et al. (1982)	Board-and-care homes	278	Lehman's QOLI	<ul style="list-style-type: none"> - Mostly satisfied in most life areas - Lower QoL than the general population - Areas of dissatisfaction - finance, social relations, safety
Baker and Intagliata (1982)	Community support services	118	Affect Balance Scale SLDS In depth interviews	<ul style="list-style-type: none"> - High levels of reported satisfaction - Dissatisfied with finances, health and leisure activities
Pinkney et al. (1991)	Ex-psychiatric patients 12 months after discharge	55	Clients' QoL Instrument Uniform Client Data Instrument	<ul style="list-style-type: none"> - 96% felt their lives had improved - Living below the poverty line - Lacking in interpersonal and employment skills
Sullivan et al. (1991)	SMI clients 13 months after hospital discharge	101	Sections of Lehman's QOLI	<ul style="list-style-type: none"> - Reported relatively high subjective QoL - Finance a source of dissatisfaction - Poor objective QoL
Shadish et al. (1985)	Nursing home residents	163	Seven subjective well-being measures; Sheltered Care Environment Scale	<ul style="list-style-type: none"> - Lower levels of well-being than the general population - Reported well-being strongly associated with the quality of the living environment
Skantze et al. (1992)	Outpatients with schizophrenia	61	SOL-I QLS-100	<ul style="list-style-type: none"> - No correlation between standard of living and subjective QoL - Sources of dissatisfaction were mental health, inner experiences, social contacts
<i>Comparative studies</i>				
Lehman et al. (1986)	99 inpatients and 92 residents in supervised community programmes	191	Lehman's QOLI	<ul style="list-style-type: none"> - Hospital patients reported a lower QoL - Two groups differed most in satisfaction with living situation
Simpson et al. (1989)	11 patients in acute wards 10 residents in a hostel 13 in group homes	34	Lehman's QOLI	<ul style="list-style-type: none"> - QoL was lower on the hospital ward than in the other two settings
Oliver and Mohamad (1992)	17 in staffed hostels 32 in boarding out homes 12 in group homes	61	Adapted Lehman's QOLI (Lancashire QoL Profile)	<ul style="list-style-type: none"> - No difference in reported QoL among samples in the three care settings
Bigelow et al. (1991)	1,154 clients from 24 mental health programmes 190 community residents	1,344	QLQ	<ul style="list-style-type: none"> - QLQ distinguished between different client groups - QLQ discriminated between clients and non-clients - QLQ discriminated among communities with known QoL differences
<i>Repeated-measures studies</i>				
Okin et al. (1983)	31 clients discharged into group homes 10 hospital patients	41	Six subjective Qol indices	<ul style="list-style-type: none"> - Significant changes in social activities, social network and capacity to meet basic needs among discharged group
Okin and Pearsall (1993)	Follow-up of 1983 sample	30	(As above)	<ul style="list-style-type: none"> - Improvements in QoL maintained at 11 years follow-up
Gibbons and Butler (1987)	11 patients from general hospital ward and 4 from psychiatric hospital ward discharged to hostel	15	Observational indices Semi-structured interview	<ul style="list-style-type: none"> - Increased feeling of freedom post-discharge - Increased amount of social interaction - Higher levels of activity
Barry and Crosby (1996)	65 long-stay inpatients, follow-up of 29 in community and 15 in hospital	44	Adapted Lehman's QOLI (Bangor QoL Schedule)	<ul style="list-style-type: none"> - Increased satisfaction with living situation - Increased freedom and independence - Improved living conditions, social relations and leisure activities

Comparative studies

A number of comparative studies have also been carried out investigating the impact of different treatment settings on the quality of life of chronic psychiatric clients. Lehman et al. (1986) compared 99 randomly chosen inpatients with 92 randomly chosen residents in supervised community programmes. All client groups suffered from chronic mental health problems, and the two groups were split into four cohorts on the basis of their length of stay in their current settings (under or over 6 months). Using Lehman's QOLI (Lehman et al. 1982) to assess objective and subjective indices of quality of life, finances were found to be the most consistent source of dissatisfaction for all client groups. Comparisons between the groups revealed that regardless of length of stay, the community residents perceived their living conditions more favourably. Overall, the hospital patients reported a lower quality of life than the community residents, and the two groups differed most in their satisfaction with living situation. However, discriminant analysis of the four subgroups revealed that the major discriminating variables were demographic and clinical characteristics and certain objective conditions. Lehman et al. (1986) point out that the results should be interpreted cautiously as the patients' current living situation was dependent on their clinical condition and not on random assignment.

Simpson et al. (1989) have compared the quality of life of clients in three different care facilities in south Manchester. The quality of life of 11 patients in acute wards in a district general hospital, 10 residents in a hostel and 13 residents in group homes were assessed using Lehman's QOLI. The client groups were not randomly allocated to the three types of facilities and placement within the care settings corresponded to the severity of the clients' psychopathology. Based on these relatively small sample sizes, the findings show that residents' quality of life was significantly lower on the hospital ward than in the other two settings. Residents in group homes expressed higher levels of general well-being and subjective satisfaction, while hospital acute wards seemed to have the highest levels of victimisation. Residents in the hostel felt that their environment was more socially cohesive and comfortable and they reported higher levels of satisfaction. Both this study and the study by Lehman et al. (1986) point to the problematic living conditions in psychiatric hospitals and the increased risk of assault, which obviously detracts from inpatients' quality of life. These findings draw attention to the problems faced by hospitalised patients and help to place the findings from community-based settings within a larger context.

Oliver and Mohamad (1992) conducted a small comparative survey of the well-being of former psychiatric patients living in three different types of residential accommodation in the United Kingdom: staffed hostels, boarding out homes and group homes. In total, 61

psychiatric clients were interviewed, using an adapted version of Lehman's QOLI, later known as the Lancashire Quality of Life Profile (Oliver 1991). The results show that in every domain more than 50% of respondents reported themselves as being, at least somewhat satisfied. Levels of global well-being were reported as being essentially positive, with 57% viewing their present life favourably. Living situation was generally regarded as an area of high life satisfaction. Overall, despite the reported differences in both personal characteristics and qualities of the residence, no systematic differences were noted among the sample in either global subjective well-being or satisfaction with specific life domains. The authors concluded that although the nature of the provision in the three types of setting differed substantially in accordance with residents' characteristics, there were no significant differences in the reported subjective well-being of the residents.

Bigelow et al. (1991) report on a study spanning several years, 24 mental health agencies and more than 2,000 interviews, designed to measure performance of mental health programmes in the State of Oregon. Using the Quality of Life Questionnaire (QLQ) developed by the authors, interviews were carried out with clients in treatment at community mental health programmes throughout the state and with 190 community residents from the same districts. Employing the community sample as a comparator, Bigelow's study sought to validate the QLQ by discriminating between persons requiring mental health services from those who do not. Uniquely among studies, the findings clearly demonstrate the practical validity of the instrument, showing that scores from the community sample were higher than those of post-treatment clients, which in turn were higher than those of pre-treatment clients. It was found that the QLQ distinguished among communities whose quality of life was expected to vary, i.e. respondents from the more economically depressed county reported significantly lower levels of well-being on a number of the quality of life indices. The QLQ was also found to distinguish between different client groups attending the mental health programmes; those chronically ill, those with drug and alcohol problems, and general psychiatric clients reported varying levels of quality of life. Bigelow et al. (1991) conclude that the QLQ shows good predictive and practical validity demonstrated by its sensitivity to treatment effects and its ability to discriminate between mental health and non-client groups.

The comparative studies indicate high levels of expressed satisfaction among community-based clients who are generally more positive about their current accommodation conditions than hospital residents. Despite the evidence that satisfaction measures can have a reasonable distribution (Oliver and Mohamad 1992), it is not clear how well the satisfaction measures can function as discriminant measures of the impact of different care regimes on subjective well-being.

Furthermore, the findings from these studies should be interpreted cautiously because the samples were not randomly allocated to the different placements. As a result, it is difficult to establish whether clients' perceptions of quality of life reflect true service differences between care settings or whether the reported differences are due to other factors such as client's functional status, psychopathology and personal characteristics.

Repeated-measures studies

There are a small number of repeated-measures studies in the literature that trace the same individuals as they move from one care setting to another, evaluating changes in clients' perceptions of quality of life under different care regimes. A repeated-measures design offers the possibility of examining the sensitivity of quality of life measures in registering the impact of different forms of care delivery on clients' lives.

Okin et al. (1983) have applied a pre-test, post-test control group design to evaluate the impact of community residential placement and support services on the lives of long-term patients discharged from one of Massachusetts' state hospitals. The experimental community sample constituted 31 clients who were discharged into group homes and the control hospital group constituted 10 patients. Both groups were evaluated at three time intervals—baseline assessment in hospital prior to discharge and at 2 months and 8 months post-discharge. The control group was interviewed at the same time in hospital. Six subscales, which covered only subjective indices of quality of life, were used to assess clients' perceptions of life quality before and after discharge. The psychometric properties of the scales used are not reported in the paper. Follow-up assessments at 8 months revealed that on almost all measures the discharged clients improved while the control group deteriorated. Significant changes were found in clients' perceptions of their involvement in social activities, their social network and their capacity to meet basic needs. Discharged clients adjusted well to community living and reported positive changes in their lives, even though their clinical symptoms had not changed. All but one of the community patients expressed a preference for living in the community and reported that they felt safer than in hospital. A follow-up of this sample some 11 years later by Okin and Pearsall (1993) found that these changes had been maintained. Although the sample size is small, it is encouraging to learn that 11 years after discharge the positive reactions and preference for community living reported during the 1st year are being maintained. Okin and Pearsall (1993), however, point out that the clients in this study were placed in well-staffed residential programmes and received more and better services in the community than clients in other districts.

Positive changes and an improvement in quality of life have also been reported by Gibbons and Butler (1987) in an evaluation of the impact of a move from hospital wards to a hospital-hostel. This study, which was based in the United Kingdom, also employed a pre-test, post-test quasi-experimental design. The quality of life of 11 patients from a district general hospital ward and 4 from a mental hospital ward were assessed prior to discharge and again after 1 year living in a new hospital-hostel. Data collected from a combination of direct observational methods and a semi-structured interview revealed that the hospital-hostel provided a better quality of life on the majority of indices used. Although many of the hostel residents felt lonely, they reported increased feelings of freedom, higher levels of activity and an increased amount of social interaction. These improvements appeared to be related to the greater flexibility and informality of the hostel regime compared to the hospital wards.

These findings are consistent with those reported by Barry and Crosby (1996), who carried out a prospective longitudinal study of the impact of resettlement on the quality of life of long-term hospital patients from North Wales. Using an adapted version of Lehman's QOLI, the psychometric properties of which are reported in Barry et al. (1993), interviews were carried out with a cohort of 65 long-stay patients on the hospital wards prior to discharge. Follow-up interviews were also carried out with 44 of this cohort, including 29 at 1 year post-discharge and 15 patients who were awaiting resettlement in hospital. The repeated measures design included three baseline measures at 3-month intervals in hospital and three repeat assessments in the community at 6 weeks, 6 months and 12 months post-discharge. Corroborating findings from previous studies, discharged clients reported increased levels of satisfaction with living situation and increased freedom and independence in the community settings. The impact of the move was most clearly evident from the objective life domain indices, which registered significant changes in living situation, improved levels of social contact and increased leisure activities. Apart from increased satisfaction with living situation, there were no significant changes in the subjective indices, which remained relatively stable across the hospital and community data points. However, the qualitative data on client reactions did suggest that the move had made a considerably positive impact on clients' lives and their sense of increased well-being. Ratings of psychiatric state and social functioning did not correlate significantly with global quality of life at 1 year post-discharge. The pattern of change in the quality of life measures for the discharged group was quite different from the profile of the group remaining in hospital, where few improvements were in evidence. Based on these findings, Barry and Crosby (1996) have raised concerns in relation to the sensitivity of the life satisfaction ratings when used as evaluation measures.

Commenting on the difficulties in interpreting relatively high rates of reported satisfaction and the stability of the ratings over time, they have concluded that satisfaction measures are best interpreted in the context of objective quality of life indicators and ideally as one of a range of outcome and process measures monitoring change over time.

The repeated-measures studies report consistent improvements in quality of life as clients move from traditional care regimes to community-based facilities. On the whole, clients report positive changes in their quality of life, feelings of freedom, independence and privacy, and increased social interactions and leisure activities. However, the small sample sizes in these studies should be noted, and, apart from Okin and Pearsall (1993), the follow-up periods are usually not longer than 1 year post-discharge.

Randomised prospective studies

There are few prospective randomised controlled studies of quality of life in the mental health area. A small number of studies evaluating specific treatment approaches, such as case management, have incorporated quality of life measures as part of the evaluation package. An example of one of the earlier studies that incorporated quality of life measures is Stein and Test's (1980) evaluation of the Training in Community Living programme in Madison, Wisconsin. Employing a randomised controlled design, the study evaluated the impact of an experimental Assertive Community Treatment (ACT) programme on the quality of life of an unselected sample of patients who were admitted to a state hospital. Baseline data were collected at admission and then at 4-month intervals up to 28 months using the Community Adjustment Form, for which no psychometric properties are reported. After 1 year, significant improvements in quality of life were reported for participants in the community programme, including less subjective distress and greater satisfaction with their lives. However, when the intensive treatment ceased at 28 months, there was no difference between the experimental and control groups. A recent review of ACT programmes by Olsson (1990) notes that most of the prospective randomised studies that have included subjective quality of life measures have not found significant differences between experimental and control groups and that the original Stein and Test study is the only randomised trial to report that ACT clients are significantly more satisfied with the quality of their lives than are control patients.

Theory-focused studies

Rosenfield (1992) uses the term theory-focused non-experimental research to describe her study, which

proposes a theoretical framework for identifying the critical components of quality of life for chronic psychiatric clients. Employing global quality of life measures from Lehman's QOLI (Lehman et al. 1982), Rosenfield interviewed 157 active participants of a psychosocial rehabilitation club in New Jersey about their quality of life. Programme components received and clients' perceptions of mastery were also assessed. The study aimed to identify the specific components of the programme that were effective in improving clients' quality of life and why. The findings from this study suggest that services providing economic resources and an empowerment approach to service delivery are significantly related to overall quality of life. Clients' perceptions of mastery were found to account for the impact of these components on life satisfaction. Rosenfield concludes that the elements that work in successful programmes are those that provide actual and perceived control, and they work because of their impact on clients' sense of mastery. The analysis in this study focuses only on subjective global quality of life, and the conclusions are obviously limited by the fact that data were collected only at one point in time. However, the strength of the study lies in its attempt to identify the components of services that are critical for improved quality of life and also in providing a theoretical framework of the important mediators of subjective quality of life.

Arns and Linney (1993) have also evaluated the impact of psychosocial rehabilitation programmes on the life satisfaction and self-concept of 88 clients with serious mental health problems attending a large community mental health centre in South Carolina. Using portions of Lehman's QOLI to assess life satisfaction, Arns and Linney report that psychosocial rehabilitation programmes may make a significant, though indirect, impact on the life satisfaction of clients as a result of changes in vocational status. Changes in vocational status were found to affect self-esteem and life satisfaction through modifying feelings of self-efficacy among participants on the programme. Despite the limitation of measures being taken only at a single time point, the findings underscore the importance of including clients' basis of comparison and self-perceptions in evaluating the impact of service interventions on subjective quality of life. Arns and Linney call for more studies to research which components and processes of psychosocial rehabilitation affect change in status and impact on clients' damaged self-concepts and quality of life.

Discussion

What conclusions can be drawn from this review of the evidence concerning the quality of life of community-based clients? Relating findings across studies is difficult due to differences in the populations sampled and

the variety of quality of life measures applied, ranging from single items to fully validated scales. In addition, the majority of the studies employ cross-sectional designs, which are limited in their ability to uncover causal relationships concerning the determinants of quality of life. Despite these limitations, the research to date points to a number of consistent findings.

The majority of studies report improved quality of life for clients following their discharge into supported community schemes. No study has reported a deterioration in quality of life following discharge. The majority of clients living in the community report high levels of satisfaction with living situation and increased freedom and independence, and despite problems with finance, health and social relationships, few desire to return to the hospital. The quality of the immediate living environment emerges as a very important concern for clients, specifically the extent to which it is physically comfortable and allows for a sense of independence and behavioural autonomy. Indeed, improved living conditions appears to be one life area where community residential programmes score heavily over institutional care. However, lack of money, concern over health matters, poor social and family relations, and personal safety issues consistently emerge as factors that adversely affect clients' quality of life in the community. There are clear implications from these findings for the development of programmes capable of addressing these aspects of clients' lives.

Overall, the quality of life of psychiatric clients appears to be lower than that of the general public, at least in the United States, and there appears to be relatively little difference between clients in different community residential settings. Despite the fact that researched programmes are more likely to be better planned and resourced, it is clear from these studies that the high levels of life satisfaction are frequently reported against a background of economic disadvantage and restricted social and employment opportunities. The fact that impoverished life conditions are not necessarily reflected in life satisfaction measures raises major concerns about their use as evaluation outcome indicators. The discrepancies between objective life conditions and the typically high levels of satisfaction reported by clients question the extent to which life satisfaction ratings can be accepted at face value as accurate and sensitive indicators of quality of life. The majority of studies report only modest correlations between the objective and subjective indices of quality of life. If satisfaction levels are unrelated to objective conditions, the question arises as to how satisfaction measures should be interpreted.

Campbell et al. (1976) have commented on the difficulty in distinguishing between the satisfaction of success and the satisfaction of resignation, and this seems to be a particularly important point to bear in mind when interpreting quality of life data from long-term psychiatric clients. The restricted life experiences, low

aspirations and depressed expectations of many individuals may lead them to report satisfaction with life conditions that fall below generally accepted norms. In addition, there is a whole host of factors affecting the reporting of life satisfaction such as social desirability effects and acquiescent response set. Since first raised by Baker and Intagliata (1982), the question of how best to interpret the high levels of reported life satisfaction among psychiatric clients has not been satisfactorily addressed, despite the fact that many researchers have relied almost exclusively on life satisfaction ratings to measure subjective quality of life. There is now a pressing need for studies to address these specific concerns and to resolve the question of whether difficulties in interpreting high levels of satisfaction are due to problems in measurement, research design or are intrinsic to the nature of the concept of satisfaction.

Concerning how well quality of life measures function as evaluation tools, an important methodological concern relates to the ability of quality of life measures to function as valid outcome measures capable of discriminating life areas affected by service interventions. The majority of studies are cross-sectional and do not inform about changes in levels of life satisfaction over time or the accommodation of internal standards to changes in external conditions. The small number of studies that have employed a repeated-measures design suffer from small sample sizes, and therefore, the sensitivity of the quality of life measures in measuring outcomes has not been clearly established. Barry and Crosby (1996) report that dramatic changes in clients' lives following resettlement are not captured by life satisfaction measures. The findings from this repeated-measures study suggest that improvements in quality of life following resettlement were evident in the objective quality of life indices, the qualitative data and other outcome measures used in the study, but were not reflected in the satisfaction ratings, which remained relatively stable. Similarly, findings from the small number of randomised studies evaluating the impact of specific interventions on perceived quality of life do not report significant changes, as most studies have failed to replicate the positive findings of Stein and Test's (1980) original study. Interpreting these findings leads to the difficulty of deciding whether the lack of change in the satisfaction measures is due to the failure of the service programmes to impact on the subjective well-being of clients or is due to the insensitivity of the measures. The relative stability of life satisfaction measures over time and across situations has been raised by Cheng (1988), who queries their appropriateness for the purposes of programme evaluation. There is a need for more carefully planned longitudinal studies employing multiple measures and larger sample sizes, in order to systematically investigate the sensitivity of the quality of life measures in detecting changes brought about by service interventions.

Fabian (1990) points out that the appropriate use of quality of life as an evaluation tool entails an understanding of the theoretical and methodological issues underpinning quality of life measures. With a few notable exceptions, many of the studies reviewed in this paper have devoted relatively little attention to the discussion of methodological and theoretical issues. Indeed, one is struck by the number of papers that have failed to provide information on the psychometric properties of the measures used. Despite the growing number of research studies in this area, few studies have related their empirical findings to an overall theoretical framework. As a result, many of the core conceptual and methodological issues remain unresolved, thereby limiting their utility in practical application. Recent studies have begun to identify possible mediators of subjective quality of life and to identify the critical components of services that impact on clients' well-being (Rosenfield 1992; Arns and Linney 1993). The findings from these studies are encouraging and provide a theoretical framework within which to interpret the empirical findings. A coherent theoretical framework is necessary in order to provide a greater understanding of the psychological processes by which individuals come to perceive and appraise their lives. Understanding the link between internal referents and satisfaction outcomes will lead to a better appreciation of how individuals attach meaning to their experiences, as well as how internal standards shift in response to external changes. Such theoretically focused research has an important part to play in the development of work in this area. For further discussion of theoretical issues see papers by Cheng (1988), Fabian (1990) and Barry (1996). Relating the quality of life outcome data to specific aspects of the care process also constitutes an important challenge for future research studies. Likewise, the relationship between quality of life and other evaluation outcome measures needs to be examined. The assessment of process and quality of life outcomes should proceed together if the quality of life data are to successfully inform service development.

In conclusion, this review points to the need for greater awareness of the conceptual and methodological difficulties that are encountered when using quality of life measures for the purpose of programme evaluation. The assumptions underlying current measures of quality of life need to be critically examined as the results obtained are undoubtedly influenced by how researchers have approached the measurement of the concept. Exclusive reliance on satisfaction measures to assess quality of life is problematic and may lead to particular problems when used in studies employing cross-sectional designs. Validated measures of quality of life incorporating both subjective and objective quality of life need to be employed where at all possible. In the light of the discrepancy between the subjective and objective indicators, the question of the usefulness of the two indicators in the evaluation of services needs to be addressed.

Assessing quality of life implies making a judgement of a relative kind, and this begs the question of what frame of reference should be used, an individualistic or normative viewpoint. The objective indicators tend to reflect socially accepted norms of standards of living and social functioning, while the subjective indicators attempt to establish the relative importance of different life areas for each individual in terms of their own values and preferences. In evaluating service provision for long-term clients, outcome measures such as quality of life need to establish if minimum standards of living conditions such as accommodation and food are being met and access to basic resources for daily living is provided. The adequate provision of such resources for community-based clients cannot always be guaranteed, which is why objective indicators of life quality need to be included. To date, the subjective measures of quality of life have been closely tied to these objective indicators, establishing levels of satisfaction in respect of each of the different life domains. However, the lack of correlation between the measures has raised the question of whether states of well-being do in fact have clear-cut objective counterparts, i.e. is satisfaction with social relations necessarily determined by the frequency of social contact? It may be that in order to reflect individual values, subjective measures of quality of life need to expand beyond the standard list of aspects of life deemed to be important by societal values. Simply eliciting satisfaction ratings of objective indicators may not be sufficient, and subjective indicators should be expanded to also include more individualistic determinants of life quality. The use of qualitative methods of data collection may prove a useful way of complementing the quantitative data and allowing the voice of the service user to come through unhindered by the researcher's a priori assumptions.

Clearly, the use of multiple measures over time provides a better picture of how well quality of life measures function as valid and sensitive evaluation instruments. There is a need for research studies to address the specific methodological difficulties that have been identified in the literature and to attempt to provide possible solutions. These issues are not only of interest to researchers but are critically important for anybody wishing to employ the existing instruments and to draw sensible conclusions from the data they produce. Clear interpretation of the results and their implications is vital if the concept of quality of life is to fulfil its potential of informing service development and guiding improved care practices in community mental health care.

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