Quality of Life and Social Integration of Severely Mentally Ill Patients: A Longitudinal Study

Raymond Tempier, MD, FRCPC¹, Celine Mercier, PhD², Pierre Leouffre, MD, CSPQ³, Jean Caron, PhD⁴

¹Department of Psychiatry, The Montreal General Hospital, Montreal, Quebec, Canada

Submitted: February 4, 1997 Accepted: June 18, 1997

The quality of life concept serves to measure functional changes and program outcome. Patients with schizophrenia have an improved prognosis. Is quality of life improving over time, and if so, over what period? These questions were addressed in a longitudinal study where subjective quality of life (SQOL) was rated by severely mentally ill patients living in the community and using support services located in an outlying area of Quebec. The Satisfaction for Life Domains Scale (SLDS) (Baker and Intagliata 1982) measuring SQOL as a whole and in specific domains (for example, housing, finances, social relationships) was repeated over a period of 7 y. Results show that SQOL ratings received the same scores after 7 y. Functional status was decreased, while social integration improved and more services were used. The results could be due to sample characteristics or to the ambiguity of the SQOL construct. In our opinion, extensive community-based support services may have played a key role in the maintenance of patients' quality of life.

Key Words: quality of life, longitudinal studies, psychiatric services

INTRODUCTION

Long-term mentally ill patients who live outside institutions need continuing support in several areas of their everyday life, such as housing, food supply, budgeting, and social relationships. A network of both professional and nonprofessional services and resources, which form a community support program, is considered the best solution to address these needs, but these resources can be costly. With recent budget cuts, fewer funds for health care expenses are available. For these reasons, the evaluation of services and resources should be a priority for clinicians and health care managers, as government bodies may ask for proof of their efficiency.

Evaluation of such community programs is usually a complex endeavor. Community care for chronically mentally ill patients is linked with various agencies and resources. It involves many tasks ranging from symptom and medication management to housing and training in community living.

²Psychosocial Research Division, Douglas Hospital, Verdun, Quebec, Canada

³Department of Psychiatry, Malartic Hospital, Malartic, Quebec, Canada

⁴University of Quebec in Abitibi-Temiscaming, Val d'Or, Quebec, Canada

Paper presented at the 5th Congress of the World Association of Psychosocial Rehabilitation, Rotterdam, The Netherlands, April 1996.

Address for correspondence: Dr R Tempier, Department of Psychiatry, The Montreal General Hospital, 1650 Cedar Avenue, Montreal, OC H3G 1A4.

Evaluations of such community support programs are usually conducted with limited resources and under conditions unfavorable for precise measurement (Bigelow and others 1990). Outcome measures are, therefore, not easily determined. Simple outcome measures, such as hospital readmission rates, give an indication of community tenure, but readmission rates are unsatisfactory because they may reveal more about the mental health system and economic conditions than the clinical status of the patient (Becker and Diamond 1995). Readmission rates are not only related to patients' functional status: other factors play a role. For example, bed availability and accessibility have an influence on the readmission rates (Salomon and Doll 1979). Readmission rates should be used only with other outcome measures.

Measuring quality of life represents a viable means of measuring programs (Lehman and others 1986; Lehman 1988; Malm and others 1981). In a review of treatment programs for schizophrenia, Goeree (1996) wrote that in Canada, quality of life was considered an important, if not the most important, measure of outcome of these programs. Living a life of quality is also a legitimate goal for patients with long-term mental illnesses. Services providing community support should help them reach this goal.

Two types of indicators define quality of life: 1) the objective indicators, including object possession and income, and 2) the subjective ones, including satisfaction and feelings of well-being. The 2nd indicators are very important because they directly reflect patients' points of view. SQOL, a multi-dimensional construct, focuses on patients' happiness with life in general and in several life domains (housing, health, budget). Measuring each domain as a separate entity is important, therefore, because the association of both subjective and objective indicators is far from consistent (Lehman and others 1982).

Deinstitutionalization has allowed persons with mental disabilities to live in community settings, but they are far from being integrated into community life, many of them choosing passive recreational activities such as watching television (Dossa 1989). Integration is a complex process. A relationship between an individual and a society or group in which he or she is placed is developed within the integration process. The environment plays a major role in one's quality of life, and this association is referred to as the person–environment fit (Zautra and Goodhart 1979). Social integration could be considered an objective measure of quality of life.

Level of functioning is another important outcome measure. Functioning includes symptoms, signs, and functional disabilities in the performance of activities of daily living. One well-known instrument for measuring functioning is the Global Assessment Scale (GAS) (Endicott and others 1976).

Several longitudinal studies showed a positive long-term outcome of schizophrenia (Ciompi and Muller 1976; Bleuler 1978; Huber and others 1979; Harding and others 1987). In the Harding study (1987), after years of follow-up and community living, 60% of patients with schizophrenia were generally functioning well, with a mean GAS score of 61. None of these longitudinal studies included an assessment of patients' quality of life, however. Fabian (1990) underlined the need for longitudinal studies on quality of life. Some studies (Pinkney and others 1991; Solomon 1992; Gerber and others 1994), however, showed an improvement of quality of life for patients' living out of rather than in institutions. To our knowledge, longitudinal comparisons of quality of life for patients who were already deinstitutionalized are rarely conducted. Our group (Mercier and others 1992) studied the quality of life of chronic patients living in the community after 1 y. We found that patients' SQOL ratings did not show any variation. So we wondered if quality of life was improving over time, and if so, over what period?

This paper focuses on the variation, over a 7-y period, of the quality of life of chronically mentally ill patients benefitting from community support services. Other outcome data, such as use of services, global functioning, and medication profiles, were also recorded.

METHOD

This study was a duplication of a quality of life survey done in 1987 with the same cohort of patients. Face-to-face interviews were completed by the original interviewer, who already worked with similar patients and was trained in mental health.

Setting

This study took place in 2 cities in Abitibi, an outlying area of Northwestern Quebec: Malartic (4326 inhabitants) and Val d'Or (23 842 inhabitants). At the time of the study, support services for the mentally ill patients in each city consisted of a mental health clinic, a community drop-in center, several foster homes, and supervised apartments. Housing services also included a halfway house and a hostel. A vocational program offered volunteer work, job training, and job placement. Several nonprofessional caregivers (that is, landlords, shopkeepers) managed patients' money, medication, and basic hygiene.

The total number of patients with a chronic psychosis who were registered in the 2 clinics was approximately 350. Roughly 100 patients were registered in the Malartic clinic at the time of the study.

Sample

All the patients surveyed in 1987 (N = 97) met 4 criteria: 1) age of 18 y or older, 2) DSM-III-R diagnosis of a chronic psychosis, such as schizophrenia, 3) at least 1 hospitalization in the local psychiatric hospital, 4) an active chart open in 1 local clinic (Mercier and others 1992). The same criteria applied for the 1994 survey. A few patients (n = 5) were hospitalized for more than 1 mo, so they were excluded at the time of the interview. Since the 1987 survey, 8 patients died of medical illnesses, and 17 charts were closed. Four patients were hospitalized during the 1994 survey period, and 3 patients refused to participate. This left 60 patients who were interviewed in 1994. After the nature of the procedure was fully explained, each of these 60 patients gave informed consent to participate in the study.

Measurement instruments

Quality of life

To measure SQOL perceptions, the SLDS (Baker and Intagliata 1982) was used in face-to-face interviews. The SLDS, a 16-item questionnaire, is adapted from Andrews and Withey's (1976) Delighted-Terrible Scale. Baker and Intagliata (1982) used the SLDS for program evaluation research in the Community Support Program in New York State. This questionnaire gives a global score of satisfaction with life in general or as a whole, and an index of satisfaction regarding 15 life domains. Domains are home, the neighborhood, services of the neighborhood, food, clothing, health, finances, relations with family members, with friends, with coresidents, with others overall, love life, their main daily activity, leisure activities, and outings. The question "How do you feel about . . .?" is answered using 7 different stylized faces, from the most smiling to the saddest face, on a 7-point Likert scale.

Lehman and others (1982) reported internal consistencies between 0.74 and 0.87 for the Delighted-Terrible Scale on a sample of chronic psychotic patients. A French version was carefully developed and tried with success (Mercier 1989). Results for the French version showed an even better homogeneity ($\alpha = 0.92$). A principal component factorial analysis identified 5 factors. Items' weights were between 0.42 and 0.85 and significant ($P \le 0.01$). Discriminant validity was excellent, permitting the discrimination of psychiatric patients from the general population (Caron and others, forthcoming).

Social integration

Social integration was measured with the Activity Pattern Inventory (API). The API was developed to measure the impact of rehabilitation services on patients with a wide range of disabling conditions, including mental retardation,

Table 1

Demographic characteristics of long-term mentally ill patients (N = 60) benefitting from community support services

Support service		
Characteristics	n	%
Gender		
Men Women	30 30	50 50
Age (y)	46.9	(10.9) ^a
Language		` ,
French English	59 1	98.3 1.7
Status		
Single/widow Married (legally or common law) Divorced/separated	34 15 7	56.6 25.0 13.3
Income		
< \$6000/y > \$6000 to \$12 000/y > \$12 000/y	45 5 9	76.6 6.7 16.7
School years	8.9	$(3.7)^{a}$

a(SD)

in a broad array of service settings (Brown and others 1980, 1984). The API measures activity patterns of time use and participation in the context of home and community (Brown and others 1984), and it measures the diversity and frequency of daily activities during a regular week. This inventory records 125 activities that were grouped into 6 principal categories: vocational activities (work, education, and rehabilitation), quiet activities (sitting calmly, doing nothing, taking naps, waiting for people to come or for events to occur, or daydreaming), personal health, domestic activities, social and recreational activities, and traveling. Only the sections on work, education, rehabilitation, and recreative activities were used as social integration indicators. Given that such activities involve the physical and social environment, they represent, to our knowledge, good indicators of the interaction of patients with their environment. In contrast, domestic activities and quiet activities are home-based and show fewer environmental interactions.

Service use

A grid developed by Mercier and others (1992) was used to collect data on the type and frequency of all services used by patients. This grid lists 78 support services, which are grouped into 2 categories: 1) specialized services for patients only (for example, group homes, drop-in centers, clinics) and 2) nonspecialized services (sports clubs, libraries) used by the community. Services are listed according to 12 life

 $Table \ 2$ SQOL scores at 7 y for long-term severely mentally ill patients (N = 60) living in the community

	Mean scores (SD)				
How do you feel about:	1987	1994	t test	df	P value
Γhe place you live?	5.7 (1.5)	5.8 (1.7)	0.19	59	0.89
The area?	5.7 (1.5)	5.8 (1.4)	0.55	59	0.58
our food?	5.4 (1.8)	5.7 (1.6)	0.90	58	0.37
our clothes?	5.8 (1.4)	5.9 (1.5)	0.21	59	0.83
our health?	5.1 (1.9)	5.1 (1.9)	0.05	59	0.96
eople you live with?	5.9 (2.1)	5.3 (1.8)	1.63	59	0.11
our friends?	5.6 (1.5)	5.5 (1.4)	0.40	59	0.68
our love life?	4.8 (2.0)	4.7 (1.9)	0.30	57	0.76
elationship with family?	5.2 (1.9)	5.1 (1.8)	0.20	59	0.84
he way you get along with others?	5.5 (1.4)	5.5 (1.9)	0.12	59	0.90
our activities?	5.2 (1.8)	5.5 (1.7)	1.06	59	0.29
he way you use your leisure time?	5.1 (2.0)	5.7 (1.9)	1.65	59	0.10
/hat you do outside for your leisure?	5.8 (1.5)	5.6 (2.0)	0.59	59	0.56
ervices and facilities of your area?	6.1 (1.4)	6.1 (1.6)	0.06	59	0.95
our finances?	4.6 (2.2)	5.2 (2.1)	1.54	59	0.12
our life in general?	5.3 (1.7)	5.3 (1.8)	0.00	59	1.00

domains: housing, activities of daily living, transportation, finances, health care, legal domain, work, education, rehabilitation, leisure activities, socialization, and other services. For leisure activities, the use of services is extended to a 1-week period, while health services and information services were extended to more than a 1-y period.

Other measures

Clinical characteristics such as diagnosis, medication, and number and length of hospitalizations were recorded from chart reviews. As well, the GAS (Endicott and others 1976) was also scored by the interviewer at the end of the interview.

RESULTS

Sociodemographic characteristics

Of the 60 participating patients, 50% were women. Demographic characteristics are presented in Table 1. Patients' mean age (\pm SD) was 46.9 y \pm 10.9 y. Most patients were single (56.6%), and most (76.6%) were in a low socioeconomic class, having an annual income of less than Can\$6000. Mean number of years' attendance at school was 8.9 y \pm 3.7 y. Half the participants (n = 30) lived in Malartic, the other half in Val d'Or. In the original (1987) cohort, 47 patients were living in Malartic and 45 in Val d'Or. Patients did not differ in gender, language, or level of education from

the patients who were part of the original cohort. The non-participants (n = 32) from the original cohort were more often single (91.9%) (χ^2 = 41.2, df 2, $P \le 0.01$) and poorer (96.4% earning less than \$6000/y) (χ^2 = 6.15, df 2, P = 0.05).

Clinical characteristics

DSM-III-R chart diagnosis included schizophrenia (63.3%), schizoaffective disorder (15.0%), paranoid delusional disorder (3.0%), major affective disorder (13.3%), and other diagnoses (5.4%). The patients' mean GAS score in 1994 was 45.4 ± 17.9 . On the GAS definition of categories, a score of 41 to 50 corresponds to "any serious symptomatology or impairment in functioning that, most clinicians would think obviously requires treatment or attention (eg. Suicidal preoccupation or gesture, severe obsessional rituals, frequent anxiety attacks, serious antisocial behaviour compulsive drinking)." The mean GAS in 1987 was 57.2 ± 11.1 . In 1994, the global functioning was lower (t = 4.32, df 57, P < 0.001). In addition, the nonparticipating patients (n = 36) had a mean GAS of 51.4 ± 11.3 in 1987, and their functioning did not differ from that of the participants in this survey (t =2.41, df 92, P = 0.18).

Based on chart review, hospitalization rates during the 1987–1994 period were as follows: no hospitalization 31.7%, 1 hospitalization 20.0%, 2 to 4 hospitalizations 21.6%, more

than 4 hospitalizations 13.4%. For 13.3% of patients, this information was missing. The average number of readmissions was 2.4 ± 3.2 . The mean length of hospital stay was $173 \ d \pm 282 \ d$ during this period. Most of the patients interviewed (63.3%) were hospitalized in psychiatry without being on closed treatment.

Medication characteristics

Most of the participants (95%) were prescribed psychotropic medication. When asked, 90% confirmed that they took their medication. The great majority (86.7%) had been prescribed antipsychotic medication, and about half (48.3%) took an antiparkinsonian medication. There was an increase of 7% in the prescription of antidepressants, and an increase of 10% in the prescription of benzodiazepine between 1987 and 1994. Almost half (43.3%) took the same medication as in 1987. The mean daily dosage of antipsychotic medication in chlorpromazine equivalents (Butler 1987) was comparable in 1994 (376 mg/d \pm 375 mg/d) with 1987 (457 mg/d \pm 548 mg/d) (t = 1.31, df 50, P = 0.19). In 1994, only 18.3% patients complained about any side effects of their medication.

SQOL

As seen in Table 2, SQOL as a whole received a mean intermediate score, showing that patients are rather satisfied with their life. In 1994, mean scores for the domains of patients' homes, their neighborhood and its services, food, clothing, and the way they use their spare time were rated at 5.7 or higher. Satisfaction with their health, the people they live with, their friends, the relationship with their family, the way they get along with others, their daily activities, their activities in the community, and their finances received scores between 5.1 and 5.6, indicating less satisfaction within these domains.

Compared with 1987, the patients' satisfaction with life as a whole did not vary, and there were no differences in any scale domain.

Social integration

Patients performed a mean number of 10 different activities each week for a total mean number of 126 activities per week in 1994. In 1987, they did almost the same mean number of activities (123 activities per week). During a normal week, they stayed out of their home during weekdays for a mean number of $18 \text{ h} \pm 15 \text{ h}$ in 1994, whereas in 1987, they stayed out 20 h \pm 15 h per week. On weekends, they went out, on average, for $10 \text{ h} \pm 12 \text{ h}$ in 1994, and $7 \text{ h} \pm 6 \text{ h}$ in 1987. There was no difference between 1994 and 1987 for their outings on weekdays and weekends. Patients spent less

Table 3

Comparison of utilization of services at 7 y
of 60 long-term severely mentally ill patients living
in the community

	Mean sco		
Services	1987	1994	t test
Health	1.35 (0.89)	2.31 (1.03)	5.93
Rehabilitation	0.05 (0.22)	0.83 (0.78)	7.18
Community resources	0.55 (0.56)	0.95 (0.85)	3.11
Leisure activities	0.15 (0.40)	0.60 (0.80)	3.55
Total	3.30 (2.10)	6.76 (3.06)	7.89

The P value for all comparisons was < 0.001.

time watching television at home in 1994 (14 h \pm 13 h per week) than in 1987 (17 h \pm 14 h per week). Patients went out less often to use general services (shops, banks) during the week: in 1994, they used fewer services (5.60 \pm 3.92) compared with 1987 (11.70 \pm 3.43) (t = 1.71, df 59, P \leq 0.02). In 1994, however, they went out more often for leisure and social activities (restaurants, movie theaters) (t = 2.55, df 59, P \leq 0.02).

Service use

In 1994, patients used between 2 to 14 services. On average, they used 6 community services (Table 3), relying primarily on 3 different types of services (2.96 ± 1.70) . One-fourth of the patients used services addressing basic needs (house maintenance, room and board, meals, grocery help). More than three-quarters of them (78%) used a health service, and almost two-thirds (63%) used a rehabilitation service. About half (48%) received supervision or assistance with their budget. Twenty-three percent sought legal aid services (that is, defense of rights, legal aid, police); 42% used nonspecialized leisure services (community, sport, or cultural centers); 66% went to a community resource; and 15% used transportation means (bus, taxi, friends, or family cars). Very few of the patients (3%) used a vocational service (work skills training, job searches).

In 1987, participants used, on average, 3.3 ± 2.1 community-based services of 2 types (see Table 3). In 1994, they used services that were more diverse (t = 4.07, df 59, $P \le 0.001$), and they also used more community services geared to the general population (2.8 ± 1.8) compared with 1987 (0.5 ± 0.8) (t = 8.58, df 59, $P \le 0.001$). Specialized services for psychiatric patients were also used more often (3.9 ± 2.4) compared with 1987 (2.8 ± 1.9) (t = 2.90, df 59, P < 0.005).

DISCUSSION

Community-based outpatient services were available to long-term mentally ill patients during a 7-y period. Use of professional and nonprofessional services and social integration were higher after 7 y. To our surprise and contrary to results from longitudinal studies (Harding and others 1987), the patients' global functioning decreased over time. Rating discrepancies are unlikely to explain lower functioning, since the same interviewer conducted the 2 series of interviews. The main result of this study was that SQOL remained the same after 7 y. This result may be attributed to the stability of the patients' lives. Most subjects lived in the same town, were registered in the same clinic, and were followed by the same clinicians over the years. Many of the patients living in a small town environment did not tend to move or drop out from the services that supported them. On average, they were in their late 40s, which could affect their SQOL scores because older patients have fewer expectations and are more satisfied with their life than their younger counterparts (Mercier and others, forthcoming). Most of them were not hospitalized; those who were had been hospitalized only once. Although the same dosage of antipsychotic medication was prescribed during this period, most patients were satisfied with their medication.

In this study, patients continued to be satisfied with their life as a whole. Patients also did not judge the satisfaction with several life domains differently after 7 y. They still enjoyed their material condition and their social relationships, but they reported their love life as less enjoyable. Social integration improved: patients went out more often for leisure and social activities and less often for basic needs. These results could reflect better organization in getting basic items and an improvement of their social integration for leisure activities. Patients used more nonspecialized services in 1994 than in 1987. Their increased use of health services could be due to lower functioning or aging. Patients' low use of vocational services may be due to their decreased interest in getting back to work. Their use of legal services increased over the 7-y study period. Patients were better informed and aware of their rights; for example, they were told more often by the community resource workers to call the police if a situation of abuse arose. Patients liked the area where they lived because they could benefit from a network of support services not far from their home. These services were in place for years in Malartic and were more recently established in Val d'Or. For a long time, the general philosophy of care in these 2 clinics was oriented toward community psychiatry and rehabilitation (Renaud and others 1991).

Although the lack of variation in SQOL ratings over time needs further clarification, we do not think that the patients interviewed were unreliable. As Awad and colleagues (1997) pointed out recently, many reports have confirmed the consistency and reliability of reports by patients with schizophrenia about their level of satisfaction and inner feelings. The stability of the measure may be attributable to the concept of quality of life itself. The definition of quality of life as a concept is still difficult to tackle, which is why so many different measurement tools exist. The concept of quality of life is viewed frequently as mostly undefinable and, consequently, unmeasurable (Awad and others 1997). There is no gold standard for its assessment (Becker 1995), and perhaps the SLDS is not sensitive enough to measure variations of SQOL.

An important issue was raised here: objective global functioning does not seem to be related to satisfaction with life. The strength of associations between GAS scores and patients' satisfaction with either life in general (r = 0.32, P = 0.012) or the health domain (r = 0.37, P = 0.004) is weak. In fact, the improvement of functioning found in longitudinal studies is significant after more than 7 y. Global functioning could decrease when patients are living in the community, but may improve later in life. In our opinion, quality of life domains are closely related to the delivery of services, and despite a rather paradoxical deterioration of their global functioning, patients' quality of life scores stayed at the same level after 7 y. Permanent support services continued to help patients living in the community to reach a satisfactory quality of life that lasted over time.

ACKNOWLEDGEMENTS

This study was conducted with a grant from the Quebec Ministry of Health and Social Services and the Regional Health and Social Services Board of Abitibi-Temiscaming (Project #93051). The authors thank the Malartic Hospital staff.

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