

# QUALITY OF LIFE SURVEY AMONG LONG-STAY MENTALLY ILL PATIENTS: PATIENT AND STAFF PERSPECTIVES

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## ABSTRACT

*In order to improve the quality of life of the chronically mentally ill patients, their treatment programmes must be individualised to address their multiple disabilities and social impairment. The patient's perception of his quality of life (QoL) can be used as an organising framework for long-term care<sup>(2)</sup>.*

*Subjects in the study included staff and inpatients from the 10 rehabilitation wards in New Woodbridge Hospital which offers a wide range of rehabilitation activities.*

*Using subjective indices, patient and staff perception of patients' quality of life were compared across several life domains<sup>(3)</sup>. Significant differences between the 2 groups were noted in areas including living conditions, relationship with others and sense of purpose in life. Most patients found the new hospital a better place in terms of its physical comfort and the medical and psychiatric care received. The implications of these findings for improving existing care for our patients are discussed.*

**Keywords:** quality of life, long-stay mentally ill, inpatient psychiatric care, psychiatric rehabilitation

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## INTRODUCTION

Over the past decade, clinicians and researchers have come to recognise that maximising quality of life is an important treatment goal in working with a population with chronic mental illness<sup>(1-6)</sup>. The integration of their assessments into programme development and treatment adds a new perspective and offers creative challenges to administrative planners and clinicians<sup>(1)</sup>.

The current emphasis is on the need to upgrade and improve mental health services in Singapore. To improve on our existing rehabilitation programmes, we need to assess our patients' satisfaction with their previous treatment programmes as well as the pattern of their current existence. The aim of our inpatient rehabilitation has always been to improve the standard of care by providing as extensive a range of services as possible given the priorities in resource allocation.

In 1993, the old Woodbridge Hospital was relocated to its present premises in Hougang. The transfer of operations from the old hospital to the new hospital was carried out in phases. With the reorganisation of Woodbridge Hospital, it now

comprises the inpatient wards in the main hospital in Hougang and in View Road Hospital and their support facilities. The New Woodbridge Hospital has a gross floor area of 1,300,000 square metres, an increase of 55% over the old hospital and is built at a cost of \$200 million. It comprises a 2-storey central spine block and 8 multi-storey ward blocks which house 68 wards with a total of 2,943 beds. Two thousand seven hundred fifty-one beds (93%) in 64 wards are for psychiatric patients. There are about 1,500 long-stay patients spread out in 31 long-stay wards. The remaining 192 beds (7%) in 4 wards are for non-psychiatric patients who have chronic medical problems requiring long-term nursing care<sup>(2)</sup>.

In our study, a group of 50 patients was followed-up for 6 months after transfer from the old Woodbridge Hospital to the new hospital. Subjects in the present study included patients and staff from 10 rehabilitation wards in Block 5 New Woodbridge Hospital. We looked at the possible factors that could contribute to the patients' perception of quality of life from both the patients' and the staff's view points<sup>(3,4)</sup>. We also examined any lack of congruency between the perceptions of ward staff and the patients. These could have significant implications in planning long-term care concerning the perceived degree of importance of the service provided as well as in engaging the patient in rehabilitation. We also studied the effects of the move to the new hospital by comparing the patients' level of satisfaction with their stay in the new and the old hospital. We hope that the findings in our study would provide helpful feedback for improving the standard of care given to long-stay patients in Woodbridge Hospital.

## METHOD

### Sampling frame

The sampling frame consisted of psychiatric patients staying in the long-stay wards at Woodbridge Hospital. Respondents were selected from a range of cultural, gender and educational background. The cross section of respondents included patients from the different inpatient wards.

Ad hoc estimate for this research indicated 70 patients to be sampled. This represented approximately 1:7 of the long-stay patients population in Block 5. However, we used random number tables to select 50 out of the 70 patients for the study. They had to be in hospital for at least a year or more and with a

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diagnosis of Schizophrenia as defined under the American Psychiatric Association (1984) Diagnostic and Statistical Manual (DSM III R) criteria. These respondents must also be able to understand and respond to simple questions and follow simple instructions. Mentally, they were not actively suicidal or psychotic at the time of survey. They also needed to have concentration span for at least 15-20 minutes and to be generally co-operative.

#### Content validity

Content validity of the quality of life (QoL) questionnaire was evaluated by a psychiatrist and 6 nursing staff. For our study purposes we adopted the quality of life checklist as proposed by Malm et al (1981), for a quick, simple recording of assessment of the various aspects of quality of life. We modified the original questionnaire for use with our population of long-stay patients. For example, the ninth section of the original checklist which dealt with religious practices of the respondents was omitted from our questionnaire. Most of our long-stay patients do not have the opportunity to go to places of worship nor do many religious groups visit them at the hospital.

The overall aim was to pinpoint the problems of a particular patient and indicate his needs. The checklist provided a simple way of organising judgements to make sure that important life domains were not overlooked.

The raters were 10 trained nurses from different ward settings, years of experience, culture, and gender. They were given the questionnaire prior to the group discussion. The raters were asked to rank each item using a 5-point scale ranging from 1 for "very satisfied" to 5 for "not satisfied". They were also asked for recommendations for feedback in relation to accuracy, appropriateness, grammar, appearance of bias and level of reliability. Standardised operational definitions were worked out to ensure a high scale reliability. The nurses who interviewed the patients were not from the same wards as the individual patients. However, the 5 nurse raters who gave their perception of the patients' quality of life were from the same wards as the patients they commented on. They knew these patients' clinical and social functioning over the past one year. The 50 patients and the ward nurses rated the items in the quality of life checklist. They indicated the degree to which each item contributed to their patients' overall level of satisfaction experienced.

The following 8 Life Domain sections were examined:

- I. **Material quality of life.** This included satisfaction with living conditions, environment, safety features and degree of communication with the outside community. Living conditions items that were considered included clothing, living space, privacy, ward routine, bathing, sleeping and toilet facilities, heat, lighting, general appearance and cleanliness of the ward, food/diet, laundry, garbage removal, general maintenance, etc (15 items); environmental factors like noise and pollution level, pleasant environment, discrimination, proximity with neighbouring ward, degree of autonomy (6 items); safety services included level of security, crime and fire precautions (3 items); communications like use of telephone, outings, parole, leave and visits by friends and family members (5 items).
- II. **Knowledge and education.** This recorded the patients' satisfaction with the availability of newspapers, magazines, books, radio and TV, etc (7 items).
- III. **Human relationship.** This looked into patients' satisfaction with relationships with relatives and friends,

etc (4 items).

- IV. **Dependency issues.** This noted patients' satisfaction with their financial and psychological dependence (2 items).
- V. **Inner experience.** This examined our patients' spiritual and religious experiences like inner harmony, pleasure from life, self-fulfilment, emotional contact, sense of purpose and sense of identity (6 items).
- VI. **Inpatient treatment care.** This covered patients' satisfaction with treatment for relieving psychiatric signs and symptoms, preventing relapse, relieving and preventing physical disease. Items considered included medical care received, general inpatient care, drug treatment, individual counselling, group psychotherapy, assistance with activities in daily living, compliance with medication, contact with medical and ward staff, etc (9 items).
- VII. **Leisure activities.** This recorded patients' satisfaction with having art and craft sessions, music and karaoke sessions, etc (4 items).
- VIII. **Work and vocational rehabilitation.** This included satisfaction with attendance at the occupational therapy department and doing ward chores (2 items).

The patients recorded their satisfaction with the new hospital using a 5-point scale: very satisfied, satisfied, unsure, unsatisfied, very unsatisfied and not relevant. The period to be evaluated was the preceding one month. Patients rated their satisfaction with the QoL items 6 months after the transfer to the new hospital. This was in terms of the conditions being much better, better, unsure or the same, worse or much worse than the old hospital. The patients and the nurses indicated the 3 most important and the 3 least important contributors to patients' satisfaction with their quality of life. The statistical analysis of the findings was done by means of using the Statistical Package for Social Sciences (SPSS)<sup>(16)</sup>.

#### Findings

All the 50 patients answered every question. However, we only considered the answers from patients who thought the questions were relevant to them.

Tables Ia and Ib show the demographic profile of our patients. Our survey of 50 long-stay chronic schizophrenic patients achieved a response rate of 100% (n=50). The majority of respondents were male 54% (n=27), and the vast majority of them were Chinese 76% (n=38). The Malays formed 8% (n=4), Indians 12% (n=6) and the other ethnic groups were 4% (n=2). The sample had a mean age of 49.39 years, with their ages ranging from 28 - 67 years. Thirty-seven percent of our patients were in the 30-39 age group. Fifty-two percent had secondary level or higher education. Two patients had university or polytechnic qualifications. Most of them had been in hospital for a mean of 7.68 years with the range of stay from 1 - 46 years.

Table II shows the comparison between the mean scores of the patients and nurse raters on the quality of life checklist. We looked for the quality of life items showing statistically significant differences in perception between staff and patient groups. Patients rated 1 for very satisfactory down to 5 for very unsatisfactory. A lower mean score indicated better satisfaction in that particular item. Staff and patients had differences in perception of satisfaction with living conditions like laundry and general maintenance in the ward. They also showed differences

**Table I – Demographic profile of respondents in survey**

Race	Male	Female
Chinese	21 (42%)	17 (34%)
Malay	4 ( 8%)	–
Indian	2 ( 4%)	4 ( 8%)
Others	–	2 ( 4%)
Total	27 (54%)	23 (46%)
Educational Level	Count	%
No education	9	18
Primary	15	30
Secondary - 'O' Level	24	48
Tertiary / Polytechnics	2	4
Duration at WBH (yrs)	Mean (SD)	Range
	7.68 ( 8.52)	1-46
Age	49.39 (10.58)	28-67

**Table II – Items on which significant differences were obtained between staff and patient groups. (The lower the mean score the better the satisfaction in that particular item).**

Item	Section	Groups				p value
		Staff		Patient		
		Mean	SD	Mean	SD	
Laundry	I	2.1	0.52	1.9	0.51	0.03
Maintenance	I	2.0	0.20	1.86	0.35	0.04
Visits	I	3.07	1.27	2.49	1.02	0.03
Parents	III	3.17	1.26	2.32	1.07	0.03
Relatives	III	3.13	1.13	2.44	1.05	0.05
Sense of purpose	V	2.63	0.88	2.2	0.65	0.02
Medical care	VI	2.11	0.32	1.86	0.35	0.02
Individual counselling	VI	2.31	0.71	2.08	0.53	0.03

in how they viewed visits by relatives and friends. The two groups had differing feelings for purpose in life and in certain aspects of inpatient treatment. Patients' ratings consistently exceeded those given by staff across all the above life domains. Patients also appeared more satisfied with their living conditions, visits by their family and friends, medical and psychiatric treatment as well as their sense of purpose in life when compared with their nurse raters.

We also compiled and analysed the 3 most important and the 3 least important items identified by the 2 groups of respondents. The staff group perceived one work-related item ie attendance at the Occupational Therapy Department as well as comfortable living conditions and good food as important factors contributing to well-being. The patient however, emphasised good living conditions, including food and sleep, the ability to work and the availability of money as significant to well-being. Some patients also commented on the importance of receiving good medication.

For both groups, supportive family and social ties as well as the availability of outside communication like going on outings and leave were important contributors to achieving well-being. Moreover, for the staff group, experiential factors like a peaceful life and fulfilment of psychological needs were important factors for a satisfactory quality of life but this was not crucial for the patient group.

However, both groups thought that the availability of leisure activities contributed little to satisfaction.

Table III compared the patients' perception of their stay in the new hospital with that in the old one. The ratings given for

**Table III – Comparison of mean life ratings of patients for new and old Woodbridge Hospital.**

Life Domains	New Woodbridge Hospital <sup>1</sup>		Old Hospital <sup>2</sup>	
	mean	Factor analysis (coef α)	mean	factory analysis (coef α)
Material well being (29 items)	1.86	0.82	1.95	0.79
Knowledge & education (7 items)	1.91	0.79	1.68	0.8
Relationships (4 items)	1.57	0.62	1.2	0.71
Dependency (2 items)	2.43	0.49	2.26	0.47
Inner experience (6 items)	2.11	0.56	2.09	0.69
In-patient care (9 items)	1.85	0.46	1.82	0.72
Leisure (4 items)	1.24	0.64	1.28	0.72
Work/vocational rehab. (2 items)	0.98	-1.5	0.94	-0.96

<sup>1</sup> Mean life domain ratings for the new Woodbridge Hospital ranged from 1, for very satisfied to, 5 for very dissatisfied. Patients were asked to give a 0 rating for items not considered relevant to them.

<sup>2</sup> Mean life domain ratings when comparing new hospital with old hospital ranged from 1, for much better, to 5 for much worse. Patients were asked to give a 0 rating for items not considered relevant to them.

the New Woodbridge Hospital are mean values for the respective sections of life domains. Patients rated 1 for very satisfactory down to 5 for very unsatisfactory. A lower mean score indicated better satisfaction in that particular item. From the results obtained, clearly most patients were satisfied with the new hospital especially in terms of material well being, leisure activities, and relationships and in their level of inner peace and feeling more relaxed.

We also examined the ratings for the contents under each of the Life Domain section. Under living conditions, most patients expressed their satisfaction in areas like clothing, bathing, toilet facilities, privacy, general appearance of the ward, cleanliness, laundry, garbage removal, general maintenance of the ward and in their sleep arrangements. They were also generally satisfied with the safety services in the ward in terms of feeling secure, crime level and fire precautions.

Regarding travel and communications, satisfaction with the use of the telephone was reported by only 61% of the 33 respondents who considered this question relevant to them. The outings out of the ward satisfied 81% of the 32 patients who responded. Visits from relatives and outside friends satisfied 74% of the 39 patients who responded to this question.

For the Life Domain section covering Knowledge and Education, only 46% or 22 of the respondents were satisfied with the availability of books in the ward. Twenty-eight percent of the 35 patients (for whom this question was relevant), replied that they were not satisfied with the availability of newspapers in their wards. However, the majority of the patients expressed their satisfaction with the television and radio sets in the ward. Most of the patients also reported satisfaction with the music and karaoke sessions held in the wards (97%).

However, leisure activities like art and craft, hobbies and games contained some deficiencies. Twenty-four percent (6 out of the 25 patients for whom this was relevant) reported unhappiness at the availability of art and craft session. Seventy-

eight percent (21 out of 27 patients) reported satisfaction with their hobbies and games.

The major concern noted under the vocational rehabilitation section was the small number of patients from the long-stay wards actually attending occupational therapy (OT). Only 14 patients considered this was relevant to them. However, of those who attended, 13 of them or 93% expressed that they were satisfied with their performance in the OT department. The majority 94% (34 out of 36) reported satisfaction with the ward work they were doing.

Patients also rated their satisfaction with the Life Domain items 6 months after the transfer to the new hospital. Generally, patients were more satisfied with the new hospital in terms of material well being, availability of reading materials, leisure activities, relationships and inpatient care. There were lower satisfaction ratings for the life domain covering inner experiences and dependency when comparing the new hospital with the old. Also a rating of less than 1 was noted for the life domain covering satisfaction with work rehabilitation. This was most likely due to the fact that most of the long-stay patients did not attend occupational therapy in the old hospital.

## DISCUSSION

The aim of rehabilitation is to improve the standard of care given to the chronically ill patient by providing as comprehensive a range of services as possible, bearing in mind their multiple disabilities and social impairments<sup>(4)</sup>. These patients are vulnerable to stress characterised by dependency, by problems with living skills, with vocational rehabilitation and coping with their social environments. Maintaining an adequate quality of life is an important aspect for long-stay patients but it is still an undefined concept and there are difficulties in measuring it. A simple, unidimensional approach is insufficient, but quality of life must be judged on a series of different dimensions<sup>(7)</sup>.

Lehman, using a quality of life interview, reported evidence attesting to the reliability of responses given by chronic mental patients, and found that subjective QoL indicators were better predictors of well-being than supposedly objective indices<sup>(1)</sup>.

In our study, we used the model as proposed by Malm et al, emphasising a wide range of factors in the material and social world together with subjective experiences as contributing to the individual patient's perception of his/her quality of life<sup>(4)</sup>. Logically, their level of satisfaction must be a consequence of individual variables or factors like age, educational level, total time in Woodbridge, personality traits and individual experiences such as special types of treatment etc, and institutional variables such as the difference in the hospital milieu given the shift from the old to the new hospital, the attitude and care of the staff and the specific treatment or rehabilitation activity the patient is offered. Obviously, both individual and institutional factors must interact in determining the satisfaction of patients. Their existential situation becomes the outcome criteria.

In using the above Quality of Life Checklist as developed by Malm et al, the overall impression was that it was simple to administer and able to yield valuable information regarding patients' existence and needs in a practical way that should be readily understandable by anyone likely to be involved in caring for the schizophrenic patient.

Professional staff providing care and support for the longer-stay mentally ill patients are concerned about the rehabilitation programmes for their patients, but as the present data show, doing this without consulting the patient runs the risk of providing services that fail to address the issues the patient perceives as important<sup>(9)</sup>. Very often, patients have views regarding their life situation that vary from those held by their caregivers. Such a situation will affect and influence to a large extent the mentally

ill patients' motivation and compliance with efforts at rehabilitating them. Patient satisfaction may bear little relation to objective assessment of conditions. Furthermore, it can be questionable as to whose view - the patient's or the carer's - is correct<sup>(4,7)</sup>.

Some of the other limitations in our study included having a number of patients not answering questions they thought were not relevant to them. This could happen if they were not interested in the question itself or did not want to bother to give an answer. It might have been better if an independent person had interviewed the patients. The nurse-patient power interplay may have inhibited the patients' answers. It would also be better to do a before/after study if the transfer to the new hospital had not occurred. But on the whole, many of our chronic patients were able to answer the questions put forward to them. Items, especially under the leisure activity section, were considered relevant in some instances by less than half of our respondents. Also, the sample size of our patients could have been bigger. Although the Quality of Life Checklist used had been validated in the original study, this was not done for our local population before interviewing our patients. Hence, there is bound to be cross-cultural variations in quality of life issues across Western and Asian cultures especially in issues of conformity, the extent of the individual patient being involved and responsible for his own care, freedom of sexual expression and societal expectations. Moreover, in any attempt to measure life satisfaction, care must be taken that responses are not due to the individual's mood, social desirability, enduring temperamental characteristics, or mental state at the time of interview<sup>(7)</sup>.

We also wanted to find out whether it was merely the effect of a shift to the new hospital and not really the actual difference in the hospital milieu and treatment care which could have contributed to the overall perception of satisfaction in the new hospital. One way of checking this would be to re-interview the same patients again using the same quality of life questionnaire one year later to check whether the patients' perception of their quality of life had reverted back to those feelings in the old hospital.

Despite the limitations, the results showed that our patients are generally satisfied with their living conditions, the safety services and the in-patient treatment care available in the new hospital. However, they expressed general dissatisfaction with their means of communication with the outside community, especially with going on home leave and their access to telephones. This could be due to the fact that it was more difficult to access the public phones in the void deck areas of each block which utilised the phone card system and the relatively few coin-operated phones available. Phone calls to their respective families could still be made by the ward nurses but restricted to certain times of the day depending on the nurses' workload and the limited number of phones available in each ward. Some patients' relatives had expressed difficulty in locating the new hospital. Many were happy with the modern facilities but were reluctant to come and visit the patients. Our patients were also generally not dissatisfied with the availability of reading paraphernalia in their respective wards. There was no significant differences in satisfaction related to demographic variables such as age, sex and duration of present admission.

The majority of patients expressed that they were more relaxed and happy in the new environment. Most of the patients enjoyed the music and karaoke sessions held in the wards. Many of them probably did not participate in leisure activities like art and craft sessions, games and hobbies etc because of the relative lack of such activities in the long-stay wards. It could also be due to the general lack of motivation and volition that is commonly found in the chronic schizophrenic patient. It was

interesting to note that the ward staff had generally a higher expectation than their patients regarding satisfaction in visits from the families and the sense of purpose in life.

It also appeared that the patient and staff groups considered different aspects as contributing to quality of life. While the staff group perceived work, comfortable living conditions as well as experiential factors crucial for a good life, the patients listed mainly good living conditions, availability of money and the ability to work as being important to them. Both groups agreed that supportive family ties and access to outside communication were important to their well being.

Some people might question us for being concerned with the quality of life for schizophrenic patients, who form a notoriously stigmatized group<sup>(3)</sup>. But a decent life is a value in its own right for our patients as for anyone else. Quality of life has many aspects, and each one of us values them differently. The findings in this study are relevant both in the evaluation and implementation of the psychiatric treatments in the wards concerned. An important part of therapeutic planning should be to find out which features of the quality of life checklist are particularly important to the patient and to the nurse raters, that is, the persons who in real life make judgements that can have a significant impact on the patient. Given this difference in viewpoint between staff and patients as to what are the major contributors of quality of life, additional input after consulting patients and the setting up of priorities based on the patients' perception of his or her life situation is needed to ensure a reasonable QoL for long-stay patients and enhancing their well-being whilst engaging them in rehabilitation activities. The discrepancy between staff's and patients' views reported here and in other studies throw doubt on the way such consultations take place at present.

For some patients, it has to be questioned whether life outside the hospital is better than inside, despite their stated preferences. Any measure of the quality of life of inpatients could be distorted by negative attitudes towards their stay. General scales of life satisfaction which are relevant to the population as a whole may be of little relevance to people who have lost, or never possessed occupational status, income, or property<sup>(1,3,9)</sup>. Loss of functioning due to chronic mental illness is more difficult to measure than those due to physical disabilities. Research in the area of patient

QoL is thus important firstly to establish the standards of the quality of care that inpatients are entitled to expect given the priorities in allocating resources appropriately, and secondly, to develop objective measures to show that a quality service is being delivered. In our desire to build a mental hospital with excellent psychiatric and medical care, the importance of continuing to ensure a reasonable quality of life for patients and enhancing their subjective well-being assumes great relevance.

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