

FROM LEROS ASYLUM TO COMMUNITY-BASED FACILITIES: LEVELS OF FUNCTIONING AND QUALITY OF LIFE AMONG HOSTEL RESIDENTS IN GREECE

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SUMMARY

The pattern of mental health care in Greece is undergoing a major transformation. The Leros Projects I and II supported the development of 13 community hostels located throughout the Greek mainland. These hostels provide residential care to more than 100 former psychiatric inpatients, mainly from Leros asylum. The present study evaluates the impact of the resettlement process on the residents' perceived quality of life (QoL) together with an examination of the residents' psychiatric and behavioural functioning four years after the move from hospital. The target sample ($n = 99$) comprised of individuals who may be considered 'chronic' psychiatric patients with a long history of institutionalisation and many are socially deprived with few family ties. The residents' functioning profile indicates a range of different levels of abilities. The QoL findings show that the majority of residents (70%) perceived the movement from the traditional hospital regime to the community hostels as being a positive change and expressed their satisfaction (74%) with the new living situation. This study demonstrates that even the most dependent, chronic psychiatric patients in Greece can be maintained in community settings and are able to articulate generally reliable and valid responses concerning the impact of service changes.

INTRODUCTION

In the late 1980s the exposure of the unacceptable and distressing conditions in Leros asylum provoked considerable outrage both in Greece and internationally. The asylum, situated on the island of Leros in the Aegean sea, was established in 1958 as a 'colony for psychopaths', a place to which 'difficult' patients and those abandoned by their families would be sent. The existence these people had to endure while they were in the asylum is well documented. A survey in Leros asylum revealed the poor living conditions in the hospital with little opportunity for privacy and evidence of a large number of patients being barefooted and wearing uniforms (Madianos & Economou, 1990). In 1988 a needs survey was conducted by Bouras *et al.* (1992), which showed that the population was severely disabled and had been isolated there for a long time.

The 'Leros case', which reflected the traditional institutional-based mental health care pattern in Greece, triggered the process of mental health reform. This involved the deinstitutionalisation of large and old-fashioned psychiatric hospitals and the development

of community-based facilities. A significant part of this reform were the Leros Projects I and II (1990–1994) in which a number of psychosocial interventions were implemented in Leros asylum. This specific programme supported the development of 13 community hostels located throughout the Greek mainland. These hostels provide residential care to more than 100 former psychiatric patients, mainly from Leros asylum. The resettlement process was comprised of two major phases: the first involved a number of psychosocial interventions which took place in the asylum and lasted for four to eight months; the second phase took place in the community hostels and involved the residents' gradual familiarisation with the new environment and training in basic self-care, domestic and social skills. The main selection criteria for the resettlement process were the patients' birth place, minimum functioning level and present psychiatric state.

Despite the large scale changes implemented by the deinstitutionalisation policy there was no systematic evaluation of the impact of moving patients from the asylum regime to community-based facilities. Hence, a number of essential questions remain unanswered: What is the impact of the resettlement process on the residents' functioning and perceived QoL? What changes have taken place following the move?

This study evaluates the impact of the resettlement process on the residents' perceived quality of life together with an examination of the residents' psychiatric and behavioural functioning status four years after the move from the hospital. In the area of mental health the concept of quality of life has emerged as an important evaluative measure in assessing the effectiveness of community services for chronic psychiatric clients (Lehman, 1988; Baker & Intagliata, 1982). Quality of life researchers point out that the extent to which community-based facilities can improve the quality of life of long-term psychiatric clients is an important test of the success of the alternative services in translating their policy objectives into practice (Barry & Crosby, 1995).

The present research was designed to explore both care process characteristics and outcomes for those resettled in the community hostels in terms of behavioural and psychiatric functioning, and quality of life. The structural and functional characteristics of the community hostels together with a measurement of the social climate of the care settings were also recorded. This paper presents the preliminary findings related to the residents' outcomes.

METHOD

Research design

The present research is a cross-sectional study examining the impact of resettlement on the well-being of long-term psychiatric residents four years after the move. Lamentably, no systematic baseline data are available from the hospital prior to discharge. Hence, the present study focuses on the hostel residents' subjective experience of the resettlement process and their current QoL and well-being in the community settings.

Sample

The sample consists of former long-term psychiatric inpatients who have been moved from psychiatric hospitals to community hostels. The majority of the residents have been moved from Leros asylum. At the time of the present research, 99 former psychiatric inpatients were

registered as hostel residents. Of the group, 74 were males and 25 females, and their average age was 58 years (range 29–81).

Settings

The settings are 12 highly supervised community hostels that are distributed throughout the Greek mainland. The majority of the hostels provide 24 hours care and the staff: resident ratio is 1:2 with an average of eight residents in each hostel. A multidisciplinary team, consisting of a psychiatrist, nurses, social workers, occupational therapists, and psychologists is responsible for the running of the hostels. The hostel activities focus mainly on residents' training in domestic, social and self-care skills. Vocational rehabilitation activities took place in some of the hostels.

Research instruments

Personal Data and History Form

A standardised form which was used for the collection of information on the demographic characteristics (age, gender, etc) and the psychiatric history (age of first psychiatric contact, no. of admissions etc) of the defined group. The information was taken from the relevant case notes.

QoL interview—A Residents' View

The present QoL schedule has been adapted from existing QoL schedules (Lehman *et al.* 1982; Barry *et al.* 1993). This instrument was developed and piloted specifically for use with the target group. The adapted schedule covers objective and subjective indices of quality of life in nine life domains, together with new QoL mediators exploring self-referent concepts (Barry, in press). The objective indices refer to external life circumstances, whereas subjective indices refer to the sense of satisfaction in various life domains. The QoL mediators refer to residents' internal experiences such as self perception and perceived autonomy. Quality of interactions with staff members was also explored. In addition, transition format scales have been included in order to explore residents' perceived comparison levels between their current experiences and their previous experience in the hospital regime. A global life section and open-ended questions were incorporated in the interview schedule. Both quantitative and qualitative data were obtained. Internal consistency reliability measures were computed for both objective and subjective indices together with the QoL mediators across the various life domains. All Cronbach's alpha estimates were above .65, with the exception the 'objective social contacts', which was moderate ($\alpha = .56$).

The Rehabilitation Evaluation of Hall and Baker (REHAB, Baker & Hall, 1984)

This is a standardised scale which assesses the rehabilitation and social functioning status of psychiatric patients. Extensive information on psychometric properties of the scale are available (Baker & Hall, 1984). Internal consistency reliability measures were computed for the Greek version of the REHAB and satisfactory Cronbach's estimates were obtained (Total General Behaviour sub-scale coefficient alpha = .93 and Total Deviant Behaviour sub-scale coefficient alpha = .54).

The Krawiecka Rating Scale (KRS, Krawiecka et al. 1977).

This scale comprises eight five-point scales (0 'absent' to 4 'severe') designed to provide a clinical assessment of long-term psychiatric patients. The scale is reported as being sensitive to change with good inter-rater reliability (Krawiecka *et al.* 1977). The clinical assessment was based on the psychiatric interview that the psychiatrist or the clinical psychologist completed with each resident together with his/her clinical observation on the residents' behaviour over one week.

Community-Oriented Programmes Environment Scale (COPEs, Moos, 1988)

The COPEs is composed of 10 subscales which measure the social climate of community-oriented treatment programmes. Reliability and validity studies provide extensive information on the psychometric properties of the scale (Moos, 1988).

Hostel Questionnaire

This specific questionnaire has been adapted from an existing instrument (Crosby & Barry, 1995). This provides detailed qualitative information on the structural and functional characteristics of the community hostels. The questionnaire was carried out with the hostel managers.

Translation issues

All of the above measures were translated from English into Greek. Remarkably, the literature shows a lack of studies related to translation methodology and process. Cultural and language differences may confound the validity and reliability of the target measure. The present translation process tried to ensure conceptual, semantic, and technical equivalence between the source measure and the target measure (Sartorius & Kuyken, 1994).

The translation of the present instruments was carried out by the first author, who is fluent in English. The translation accuracy was cross-checked by a Greek psychiatrist, with a PhD from the United States and a Greek researcher in Social Anthropology, fully qualified as an English teacher and a BA in psychology. Reliability checks were carried out to ensure the accuracy of the translation. The results from the relevant checks were satisfactory.

Procedure of data collection

Of the 13 hostels 12 took part in the present study. There was an average of eight residents in each hostel. One hostel did not take part due to internal difficulties over that time period. The data collection lasted for six months (August 1994–January 1995). The time window for data collection in each hostel was one week. The author resided within the hostels during the period of data collection. Participating in the daily hostel activities, group discussions, leisure activities and spending a considerable amount of time with the residents and staff members proved a useful means of gaining insight into the everyday life of the hostel residents. The present research was well received.

RESULTS

Profile of resettled group: Demographic and clinical characteristics

The Personal Data and History Form was completed by the researcher based on the case

Table 1
Demographic and clinical characteristics of the total sample
(N = 99)

Age (years)	Mean	58.3
	SD	10.2
	Range	29-81
Gender	Males	74
	Females	25
Ever married	N	16
Age first psychiatric contact (yrs)	Mean	24
	SD	08
	Range	07-52
Total yrs hospitalised	Mean	30
	SD	08
	Range	04-45
Length of prior stay (yrs)	Mean	22
	SD	08
	Range	01-40
No. of admissions	Mean	03
	SD	01
	Range	01-07
Clinical diagnosis	Schizophrenia	77
	Epilepsy	12

notes. Of the group, 16 were, or had been married. Over half of the total sample (54%) had some primary education, 32% were illiterate and ten had secondary level education. In most cases, the family ties were broken and for almost two thirds (71%) of the residents both parents were dead. Concerning contact with family, 16 of the residents received supportive family contact and 11 had quite frequent contact, whereas 71% had either no or hardly any family contact. Based on the case notes, the majority of the residents (77) were diagnosed as suffering from residual schizophrenia, 12 had epilepsy and 25 were diagnosed as having mild learning difficulties and three severe. Almost half of the residents had received ECT treatment and four had had a lobotomy. The average length of stay prior to the last discharge was 22 years (range 01-41) and the average number of total years of hospitalisation was 30 years (range 04-45). Of the group, 58% had only two or three admissions to psychiatric hospitals. Only six of the residents were not on medication (Table 1). In general, the profile indicates a sample comprised of individuals who may be considered 'chronic' psychiatric patients with a long history of institutionalisation and many are socially deprived with few family ties.

OUTCOMES

Psychiatric state

The psychiatrist or the clinical psychologist from each hostel completed the Krawiecka Rating Scale. Due to logistical reasons, the completion of the relevant psychiatric scale was not feasible for the residents of three hostels. The means (SD) of KRS scores for the sample are presented in Table 2. The results indicate higher ratings in negative symptoms compared

Table 2
Mean (SD) of KRS scores for the
sample (N = 70)

Symptomatology	Mean (SD)
Anxiety	1.52 (1.15)
Depression	0.97 (1.11)
Delusions	1.06 (1.50)
Hallucinations	0.87 (1.35)
Poverty of speech	1.92 (1.40)
Flattened affect	1.68 (1.34)
Incoherence of speech	1.38 (1.31)
Psychomotor retardation	1.64 (1.32)

to positive symptomatology. The majority of the residents were rated as having symptoms of psychomotor retardation (57%), poverty of speech (58%) and flat affect (50%) at a mild to moderate pathological level. The levels of hallucinations and delusions were low for the majority of the residents. The symptoms of anxiety were rated at a mild to moderate pathological level with a mean (SD) of 1.52 (1.15). Finally, the levels of depression were low with a mean (SD) of 0.97 (1.11). Overall, the residents' psychiatric picture is dominated by the negative symptoms. Given their age and the long history of institutionalisation for the majority of the residents, the results are not surprising. The literature supports the strong association between negative symptoms and length of stay in a hospital regime. Long-term patients are more likely to suffer from the 'clinical poverty' syndrome or negative symptomatology (Wing & Brown, 1970).

Behavioural functioning status

The REHAB rating scale was used to provide a measure of residents' functioning or dependency level. REHAB ratings were carried out on 96 residents by the care staff workers from each hostel. Three residents were missing. The time window used for the ratings was one week spanning the period the researcher spent in each hostel. The scale constitutes two sub-scales: Deviant Behaviour sub-scale which refers to socially unacceptable behaviours and General Behaviour sub-scale which refers to five areas of basic life skills: social activity, speech skills, speech disturbance, self-care skills and community skills. The Total General Behaviour score has been suggested as the best and valid single dimension indicator of the patients' level of dependency and functioning (REHAB Manual, 1984).

Scores on Total General Behaviour sub-scale of the REHAB scale ranged from 13 to 141, with a mean (SD) of 59.4 (30.2). The Total General Behaviour sub-scale score is divided into three levels of dependency. A score of 66 to 144 indicates high levels of dependency and 41 to 65 a moderate dependency level. A score of 40 or below indicates a minimum level of dependency. The results show that 30% of the sample were rated as least dependent, 38% as moderately dependent and 32% as severely dependent. The means (SD) are presented in Table 3. Concerning the five factor scores of the General Behaviour sub-scale the results show poor levels of social activity with a large number of the residents (45%) in the severely dependent category. The self-care skills were satisfactory with a considerable proportion of the residents (45%) in the least dependent category. The majority of the residents (65%) had

Table 3
Mean (SD) of REHAB factor and total scores
for the sample (N = 96)

Factor and Total scores	Mean (SD)
Total deviant behaviour	2.16 (2.16)
Total general behaviour	59.40 (30.24)
Social activity	26.03 (12.89)
Speech skills	7.38 (5.37)
Disturbed speech	6.66 (5.22)
Self-care	13.18 (10.87)
Community skills	9.49 (4.85)

moderate community skills. Not surprisingly, given the long history of institutionalisation, more than half of the residents (53%) had poor speech skills with high levels of speech disturbance (56%).

Behaviour problems were assessed using the seven item Deviant Behaviour sub-scale. Potential scores range from 0 to 21, with higher scores indicating greater frequency of deviant behaviours. Of the group, 25% were reported as least disturbed, 40% mildly disturbed and 35% severely disturbed. The most frequently observed type of deviant behaviour was talking to self, which occurred in 48% of the residents. This was closely followed by verbal aggression (43%) and incontinence (15%).

Even though the sample constituted patients with long-term mental health problems, a wide range of total scores, 13 to 141, were obtained on the General Behaviour sub-scale of the REHAB scale. The marked variations on the Total General Behaviour score indicate that these residents were not homogeneous either in general functioning or in their ability to carry out basic skills. It should be noted that a considerable proportion of the residents fell outside the range usually considered to indicate 'resettlement potential' (REHAB Manual, 1984).

Perceived quality of life in the community hostels

In all, 54 successful interviews were carried out. Three residents were absent, ten residents declined to participate, four residents were more or less mute and one was very confused over that time. One had severe speech problems, whereas 16 had poor communication skills. The QoL findings refer to residents' perceived changes that took place following the move, perceived levels of psychological well-being, QoL mediators, objective indices of their current living circumstances, and finally their global sense of psychological well-being.

Perceived changes

As shown in Figure 1 the majority of the residents report major improvements in their current living arrangements (69%) and express positive feelings about their new lifestyle. Improved financial status is also considered to be another positive change in the residents' lives (49%). It is worth noting that almost none of the residents were receiving any financial benefits over the period of hospitalisation. The life areas that are least affected by the move are physical health and religion. Of the sample, a considerable number of residents (48%) report no changes concerning their family relations, whereas 41% report that their family relations have been improved following the move. Low response levels were obtained in relation to

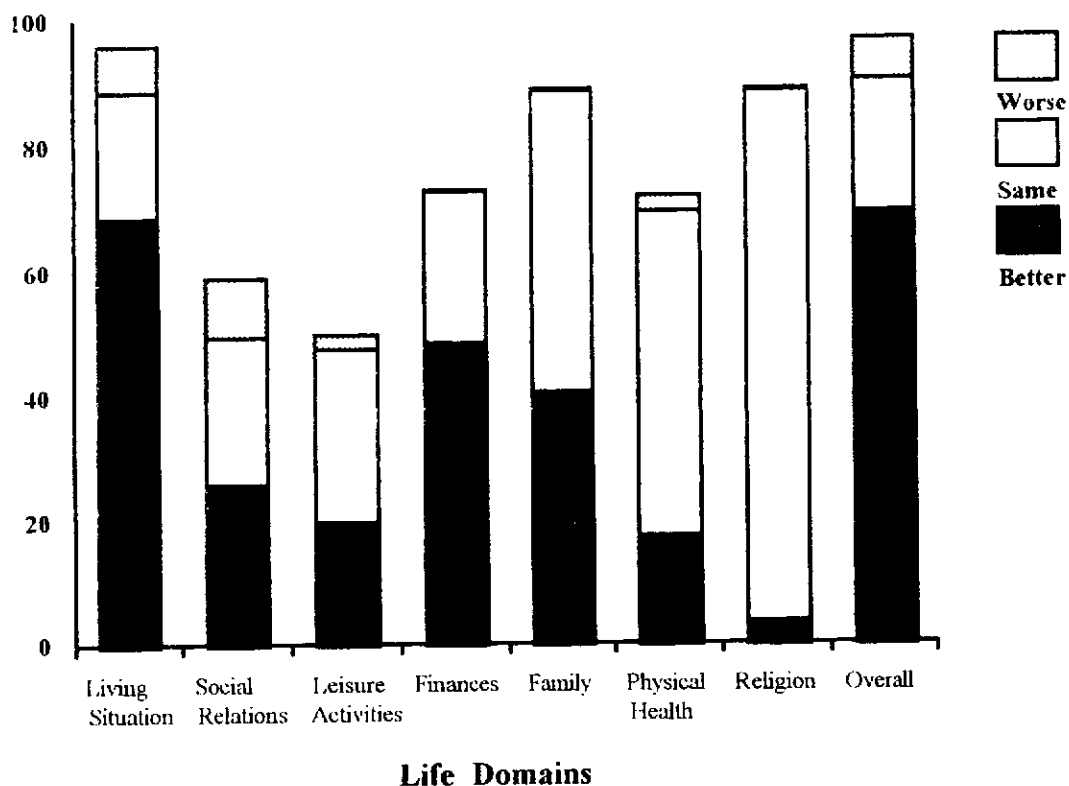


Figure 1. Residents' perceived changes across life-domains (N = 54)

perceived changes in 'social contacts' and 'leisure' life domains. Overall, the residents describe the move from the asylum to community hostels as a positive change (70%). However, there is a considerable number of residents who report that there is no change in their lives following the move (21%). Qualitative data indicate that high levels of supervision, medication and feeling like 'being in a psychiatric place' were the main reasons for justifying their perceptions of no change. These comments may indicate the danger of creating 'mini-institutions' in the community.

Perceived levels of psychological well-being

Perceived levels of satisfaction across six life domains, together with life satisfaction in general are depicted in Figure 2. Three life domains do not include satisfaction scales: safety, religion and work. As may be seen the majority of the residents (74%) are mostly satisfied with the current living arrangements and their physical health state (64%). The life areas that elicited the highest level of dissatisfaction are family relations (49% dissatisfied) and finances (30% dissatisfied). Over half of the residents (55–65%) failed to articulate judgements concerning the two domains of friendship and leisure.

QoL mediators

The internal referent items explore residents' self-perception and levels of autonomy within the facility. Quality of interactions with staff members was also explored. Most of the

QUALITY OF LIFE AMONG HOSTEL RESIDENTS

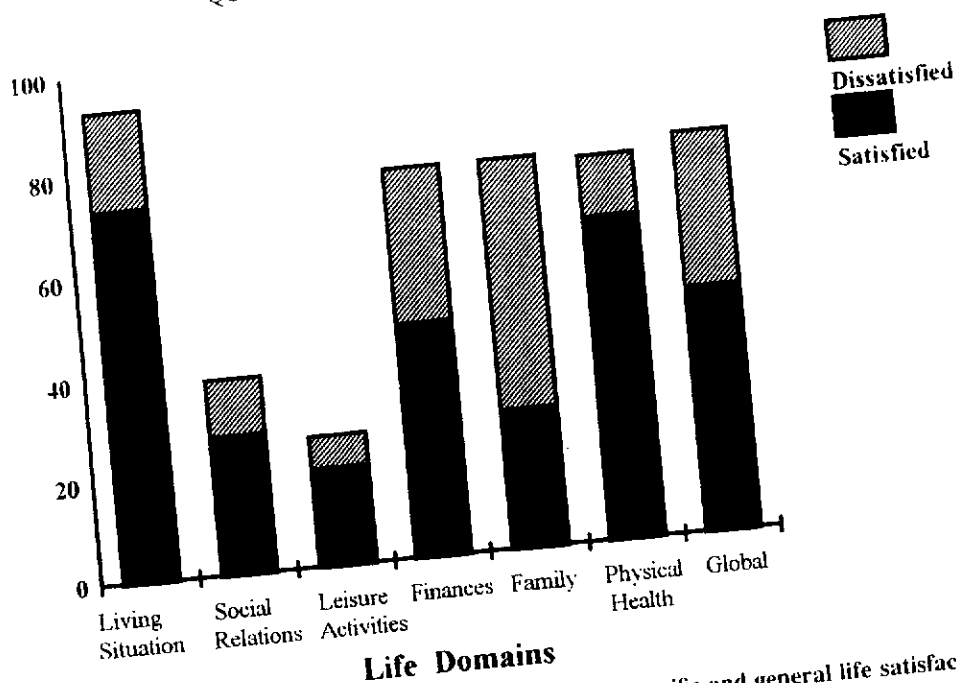


Figure 2. Residents' perceived levels of satisfaction: Domain-specific and general life satisfaction (N = 54)

residents experience feelings of self-worth and self-efficacy within the context of the hostel. However, difficulties are reported concerning their ability to cope with their family members (24%). Most of the residents appear to be quite involved in the hostel activities, even though more than half of the residents report that they are pressurised to carry out domestic chores. Freedom (63%) and levels of autonomy (61%) are reported by a considerable number of residents. The residents failed to articulate responses in relation to perceived levels of control (88%) and privacy (48%). More than half of the residents report being encouraged (58%) and respected (56%) by staff members and express their positive feeling towards the staff members.

Objective indicators

Most of the residents share their bedrooms and possess a number of personal belongings, such as clothes, photos and purses. The most frequent source of interaction is with staff members and other residents within the facility. Going for walks and watching TV are the most frequent leisure activities, whereas the least frequent is using public transport. Of the sample, only 30% report having frequent family contacts. Personal safety does not appear to be an issue. None of the residents was accused of a crime and only three residents were robbed in the previous year. Notably, only 20% of residents report having physical health problems. None is in full-time employment and 14 are working in vocational rehabilitation schemes.

Global

Overall, high levels of satisfaction were obtained in relation to global sense of psychological well-being, with 49% report feeling satisfied with their lives and 30% report dissatisfied

Interesting comments emerged when the interviewees were asked to justify their relevant global judgements:

"...Leros was like a grave...I am so glad that I am not there anymore..."

DISCUSSION

This study investigated the QoL of former psychiatric patients four years after they moved from Leros asylum to the community hostels throughout Greece. The results should be interpreted with caution because of the retrospective nature of the research design. However, the study provides a unique perspective on residents' perceived quality of life in the new care environments and raises issues for future research.

The results indicate a sample comprised of long-term psychiatric patients with broken family ties, suffering from the 'clinical poverty syndrome'. The residents' functioning profile indicates marked variations in relation to the overall levels of dependency and basic life skills. The QoL findings show that a high proportion of the residents (70%) perceived the movement from the traditional hospital regime to the community hostels as being a positive change and expressed their satisfaction (74%) with their new living situation. Only six wanted to go back to the asylum. The life areas that elicited high levels of dissatisfaction were family relations and finances. This finding is in keeping with the findings from previous American and UK studies, which indicate family and finances as main sources of dissatisfaction among resettled psychiatric clients (Baker & Intagliata, 1982; Lehman *et al.* 1982; Barry & Crosby, 1996).

Residents experienced difficulties in responding to subjective indices in two life domains: social relations and leisure activities. However, given the fact that the majority of the residents had spent more than 20 years in the asylum, their perceptions of friendship and the concept of leisure may be different from that of the 'normal' population. Residents' evaluations of these domains may be altered by their previous experiences of institutionalisation and their current expectations. Overall, there were marked variations in relation to satisfaction feelings across the various life domains, which indicate that the interview succeeded in discriminating between the different life areas. Less than half of the group (49%) felt satisfied with their lives in general.

The results of the present study demonstrate that even the most dependent, chronic psychiatric clients in Greece are able to articulate generally reliable and valid responses concerning their subjective experiences and register changes that have taken place following the move. This supports recent evidence that chronic psychiatric clients can provide reasonably reliable information about their QoL and make clear and consistent judgements about their accommodation preferences (Lehman, 1988; Thornicroft *et al.* 1993).

Furthermore the present results support the findings that long-term psychiatric clients can live in the community and enjoy feelings of freedom and independence (Anderson *et al.* 1993; Hoult, 1986; Stein & Test, 1978; Barry & Crosby, 1996). For the present sample, the movement to the community resulted in improvements in living conditions, greater personal freedom and more opportunities for interactive contact with family members, leisure and social activities. The majority expressed their preference for community living over life in hospital. However, some considerations are raised for those who did not perceive any changes in their lifestyles as they moved from the asylum to the new facilities.

CONCLUSION

The present quality of life results show that the majority of the residents have adapted well to their life in the community. This finding supports Bairaktaris' claim (1990) that the 'incurable' patient is a myth and as Murphy (1991) points out that given adequate resources and comprehensive mental health services chronic psychiatric clients do manage to live in the community successfully. However, there has been little research in Greece evaluating the efficacy of the alternative community settings and the outcome of the rehabilitation interventions from the former psychiatric clients' point of view. The present study provides a unique perspective on the outcomes of community-based care in Greece incorporating the clients' subjective experience. It is clear that there is a need for research evaluation in order to identify the critical variables of community treatment programmes which improve psychiatric clients' quality of life. This kind of evaluative research will help to translate the empirical findings into successful social policy.

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