

Research article

Psychiatric Hospital of Leros: A portrayal of the current situation

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ABSTRACT

The purpose of this study was to describe the demographic and clinical features of the inpatients currently residing at the Psychiatric Hospital of Leros. The present systematic documentation and presentation aimed to demonstrate the standard of living and healthcare conditions provided today, after the implementation of the Greek Psychiatric reform program, adhering to the principles of deinstitutionalization and community psychiatry, following the current international guidelines. In addition, we discussed the current relationship between the psychiatric departments of the hospital and the other departments and clinics in terms of providing healthcare services to chronic psychiatric inpatients in full compliance with the biopsychosocial model and its application to the unique case of Leros. The implemented patient profiles incorporated both subjective and objective factors, such as compliance with rules and treatment, self-injury, and harm to others. Furthermore, we quantified and categorized the level of care required for each patient in terms of personnel-reported activities. This parameter was assessed through the Greek version of Katz's Index of Independence in Activities of Daily Living. Simultaneously, the fundamental actions provided to inpatients by the social care and support services of the hospital were also depicted and categorized, in terms of connection to State social services, communication with the patient's families, and cooperation between the families and the hospital for the patient's healthcare needs. Furthermore, we analyzed and presented all statistically significant correlations found in our patients' characteristics. Briefly, the main results of our study show that the mean age of the 212 patients was 62.4 years old (with a standard deviation of ± 13.6 years and the longest hospitalization of 62 consecutive years) including patients from the institution's asylum period. Since 1989, the year when the psychiatric reform began in our hospital, 87 new patients were admitted, 85.1% of whom were from the southern Aegean, thus following the principle of nativeness. Intellectual disabilities and psychotic spectrum disorders were the most common disorders among the total number of hospitalized patients, accounting for 40% in each category. Regarding the 87 patients hospitalized after 1989, psychotic spectrum disorders were diagnosed in the vast majority (58 patients, 66.7%) followed by organic mental disorders (10 patients, 11.5%). The rest were diagnosed with other disorders. Somatic comorbidity and the need for care and services, especially for patients with intellectual disabilities, demonstrate how the Institution now mainly offers psychogeriatric healthcare services. In conclusion, the purpose of this study was to highlight the Psychiatric Hospital of Leros as it stands today, in stark contrast to the long-established, stereotypical depiction of asylums in the scientific and public communities.

KEYWORDS: Psychiatric reform, Leros, psychiatry, deinstitutionalization.

Introduction

The State Psychiatric Hospital of Leros has been engraved in collective memory as “Europe’s Guilty Secret.” The scathing title of John Merritt’s article in the British newspaper “Observer” in September of 1989¹ marked a pivotal moment in the history of the Institution and Psychiatric Reform in Greece. The story of the Institution officially begins in 1957 with a royal decree for the establishment of the Mental Patients’ “Colony of Leros” where a systematic transfer of patients with mental disorders from other psychiatric hospitals in the country begins. In 1965, the institution was renamed the “Psychiatric Hospital of Leros.”²

The Hospital was formed through the merger of the Psychiatric and General Hospitals on the island in 1976. The year 1989 marks the beginning of Psychiatric Reform, not only for the Psychiatric Hospital but for the entire country. Another crucial point was the merger of the Leros branch of the Homeland Institution for Social Welfare and Care (PIKPA acronym in Greek) with the Psychiatric Hospital in 1993.³

The Psychiatric Reform and the consequent deinstitutionalization drastically changed the character of the Institution. Educational groups from Greece and Europe helped in the “deinstitutionalization” of the patients, their training, and the management of their new lives outside the asylum. Many patients continued to reside in the Institution, but the focus of their subsequent care was functionality and the modern principles of community psychiatry. As a result, Leros now has a double-digit number of community mental health structures, despite only having a population of 7,000 permanent residents.

The purpose of this study is to provide a realistic, contemporary, and comprehensive depiction of the current reality of Leros’ patients. This study represents a systematic and thorough recording and analysis of the clinical and epidemiological data, as well as the precise healthcare service data received by all the patients of the Psychiatric Hospital of Leros, thirty years after the start of the Greek Psychiatric Reform.

Material and Method

The study’s methodology included both qualitative and quantitative data, which were obtained through the hospital’s information system and the electronic medical record available for each patient. In the four psychiatric sectors of the Institution of Leros, a total of 26 distinct structures of various types are included, where patients are placed based on their level of functionality and psychiatric diagnosis.

The patient’s region or country of origin (for foreign countries) was initially recorded from the demographic data. This parameter reflects compliance with the principle of locality, the right of each patient to be hospitalized close to their place of origin, which is central in social psychiatry. Subsequently, the year of admission to a psychosocial rehabilitation structure of the hospital, whether the patient was in the PIKPA. Institution before the merger and the patient’s age were recorded.

In terms of epidemiological data, records were created for the total number of years of hospitalization in the Institution, the patients’ diagnoses - psychiatric and non-psychiatric, visits and referrals to the hospital, and the frequency of hospitalizations.

Geographical regions instead of the country’s administrative divisions were selected, to demonstrate the shift from past practices to present-day hospitalization based on locality and the principles of community psychiatry. Special emphasis was placed on the changes before and after 1989, the year of the start of Psychiatric Reform for the Institution. The locality also indirectly affects a patient’s contact with their relatives, as the shorter the distance, the more frequent the visits from family members.

The psychiatric diagnoses at admission of the patients were grouped according to the tenth revision of the International Statistical Classification of Diseases and Related Health Problems (ICD-10).⁴ Physical comorbidity, as recorded in each patient’s electronic medical record, was reported for the last four years (2018–2022). A similar time limit was applied for recording the usage of other available healthcare services and the frequency of hospitalizations a patient may have had in any clinic of the hospital, regardless of the cause.

Another category investigated was that of the “difficult patient.” The definition of these patients is the subject of research and is influenced by the care framework and personal, interpersonal, and social factors.^{5,6} The psychiatric history, psychological adaptation to the accommodation, and coexistence with other patients and staff, combined with physical illnesses and the need for assistance and/or support, also influence whether a patient is designated “difficult”. For our study, we selected five parameters that help describe the management of the “difficult patient”.^{7–11} Non-compliance with medication regimen and/or living rules, self-destructiveness, and hetero-destructiveness were recorded if they occurred at least once in the last three months of the data collection period. Similarly, the parameters of “physician’s opinion” and “nursing staff’s opinion” were created. These two parameters

were created with the rationale that patients of Leros' Psychiatric Hospital have unique experiences, and it is not appropriate to compare them based on bibliographical definitions of "difficult patients" without considering their own experiences. We thus believe that the opinions of the medical and nursing staff help signify an overall "difficult patient" component that more accurately fits our patients.

Furthermore, a detailed record of the patient's self-care abilities was made. Katz's Index of Independence in Activities of Daily Living was used, a version standardized for the Greek population.¹² This scale assesses patients' functional independence or dependence by evaluating their ability to perform activities such as bathing, dressing, toileting, transferring, continence, and feeding. Each activity is scored based on whether there is self-care or complete dependence on others. The sum of the scores represents the overall score for each patient.¹³

The last group of parameters relates to the services provided by the Social Services Office of the Hospital to the patients. It includes the issuance of documents and the issuance of a social security registration number with the assistance of the Social Service. Additionally, the patients under guardianship were recorded, regardless of whether it was plenary or limited.¹⁴ Moreover, patients who were entitled to a pension or benefit were also recorded. These components were created and evaluated with the assistance of Social Service personnel and were based on the standards of social work for patients with mental illnesses.

The last component that was recorded represents one of the darkest moments in the history of the Institution. It documented whether there was successful contact between patients and their family environment within the framework of the Psychiatric Reform, as prior to the reform, the rule was to have no contact with a patient's environment. For patients where successful contact was achieved, the presence or absence of collaboration between the family members and the Social Service and

treating physicians of the hospital for the various needs of the patients was also documented.

Data collection was conducted from October 20, 2022, following the approval of the Scientific and Administrative Boards of the Hospital, until December 20, 2022.

Statistical analysis was performed using IBM SPSS Statistics (Version 26).¹⁵

Results

The total number of patients is N=212. Table 1 presents the distribution of patients across the 4 psychiatric sectors by gender, both in absolute numbers and percentages. The first (1st) psychiatric sector consists of structures that previously exclusively housed female patients, which is why there is a significant representation of females. In contrast, the fourth (4th) psychiatric sector had the most male patients from the pre-deinstitutionalization era structures. The second (2nd) sector is the former Homeland Institution for Social Welfare and Care (PIKPA), where there is an equal distribution of patients by sex.

The age range of the hospitalized patients was 21 to 104 years (mean=62.4 years, standard deviation=13.6 years). The age at admission ranged from 5 to 86 years (mean=32 years, standard deviation=15.2 years). The admission dates spanned from 1960 to 2022. Similarly, the duration of hospitalization ranged from less than one year to a maximum of 62 consecutive years.

The geographical distribution of patient origins is presented in table 2, based on the regions of the country. Since the start of the Psychiatric Reform in 1989, there have been 137 admissions involving the current chronic patients of the psychiatric hospital. Among these, 50 admissions came from the merger of P.I.K.P.A. with the hospital. Of the remaining 87 admissions, only 13 patients did not originate from the Southern Aegean region.

Table 1. Patient distribution in the psychiatric sectors by gender.

| | | | Psychiatric sector | | | | |
|--------|--------|-------|--------------------|-------|-------|--------|--------|
| | | | 1st | 2nd | 3rd | 4th | |
| Gender | Male | N | 10 | 26 | 36 | 47 | 119 |
| | | % | 8.4% | 21.8% | 30.3% | 39.5% | 100.0% |
| | Female | N | 28 | 25 | 19 | 21 | 93 |
| | | % | 30.1% | 26.9% | 20.4% | 22.6% | 100.0% |
| Total | N | 38 | 51 | 55 | 68 | 212 | |
| | % | 17.9% | 24.1% | 25.9% | 32.1% | 100.0% | |

Table 2. Patient descent per Greek region or abroad.

| | N | (%) |
|------------------------------|-----|-------|
| South Aegean | 85 | 40.1 |
| Attica | 31 | 14.6 |
| Central Macedonia | 23 | 10.8 |
| Western Greece | 12 | 5.7 |
| Peloponnese | 11 | 5.2 |
| Thessaly | 8 | 3.8 |
| Central Greece | 7 | 3.3 |
| Eastern Macedonia and Thrace | 6 | 2.8 |
| North Aegean | 6 | 2.8 |
| Crete | 6 | 2.8 |
| Abroad | 5 | 2.4 |
| Ionian Islands | 5 | 2.4 |
| Epirus | 4 | 1.9 |
| Western Macedonia | 3 | 1.4 |
| Total | 212 | 100.0 |

The admission diagnoses of the patients were grouped according to the tenth revision of the International Statistical Classification of Diseases and Related Health Problems (ICD-10) and are demonstrated in table 3.

Intellectual disability was the most common diagnosis at admission. Among the 84 patients with intellectual disability, 34 were hospitalized in the PIKPA before the merger. The 87 admissions after the start of the Reform differed in terms of distribution across diagnostic categories. The majority of them, 66.7%, suffered from psychotic spectrum disorders (F20-F29, 58 out of 87), followed by organic disorders with 11.5% (F00-F09, 10 out of 87). The remaining patients were distributed across other psychiatric diagnostic categories as indicated in table 3.

Table 3. Categories of, psychiatric and not, patient diagnoses (based on ICD-10).

| Diagnosis (ICD-10) | N | (%) |
|--|-----|------|
| Intellectual disabilities (F70-F79) | 84 | 39.6 |
| Schizophrenia, schizotypal, delusional, and other non-mood psychotic disorders (F20-F29) | 83 | 39.2 |
| Mental disorders due to known physiological conditions (F00-F09) | 14 | 6.6 |
| Cerebral palsy and other paralytic syndromes (G80-G83) | 10 | 4.7 |
| Pervasive and specific developmental disorders (F80-F89) | 6 | 2.8 |
| Mood (affective) disorders (F30-F39) | 5 | 2.4 |
| Other congenital malformations (Q80-Q89) | 3 | 1.4 |
| Pervasive and specific developmental disorders (F60-F69) | 2 | 0.9 |
| Chromosomal abnormalities, not elsewhere classified (Q90-Q99) | 2 | 0.9 |
| Mental and behavioral disorders due to psychoactive substance use (F10-F19) | 1 | 0.5 |
| Episodic and paroxysmal disorders (G40-G47) | 1 | 0.5 |
| Other disorders of the nervous system (G90-G99) | 1 | 0.5 |
| Total | 212 | 100 |

Physical comorbidity was recorded using the ICD-10 codes but was limited to the last four years. Based on the data from the last four years, 50% of the patients had experienced a physical comorbidity that required treatment. The average number of referrals in the last four years corresponded to 13.5 referrals per patient. In terms of patient care and hospital services integration, 108 out of 212 patients (50.9%) were hospitalized at least once in a hospital clinic in the last four years. For patients hospitalized in the hospital clinics, on average, there were 2.4 hospitalizations per patient.

The category of "difficult patient," as defined in the material and methods, was analyzed into five parameters, as shown in figure 1. The figure illustrates the distribution of patients for each parameter in both absolute numbers and percentages for patients who meet the criteria for each parameter.

The degree of care and self-care were categorized based on the results of the Katz Scale. Out of the total number of patients, 85 (40%) had a score indicating full functionality (Grade A) in the service and care parameters previously presented. Patients with a score of 3–5, totaling 42 (20%), had moderate impairment and required partial assistance in their activities (Grade B). Finally, 85 (40%) patients had a score of 2 or less, indicating no self-care ability and the requirement of continuous care (Grade C).

The social service provisions, as defined earlier, were divided into six axes:

1. The issuance of new documents for patients was successful in 188 out of 212 patients.
2. The issuance of the AMKA (Greek social security number) was possible for only 204 patients.

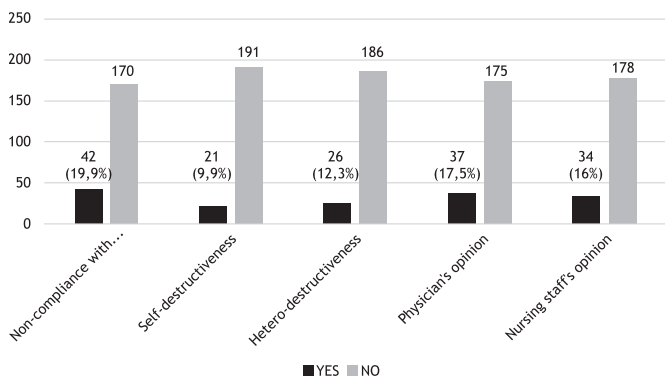


Figure 1. Patient distribution per "difficult patient" category. *Self-destructiveness: occurrences of self-harm mainly by patients with neurodevelopmental disorders. Hetero-destructiveness: occurrences of outbursts of anger with physical violence targeting other patients for the achievement of some secondary benefit by the patient.*

3. A total of 71 patients were under legal guardianship.
4. 131 patients were beneficiaries to a pension, regardless of the type of pension.
5. The familiar environment of the patients was identified in 176 out of 212 patients.
6. Collaboration and communication between the institution and the familiar environment existed only in 141 (80% of patients with a known environment).

In figure 2, the percentage distribution of each Social Service provision is bimodally color-coded on each vertical axis. The significant heterogeneity of the sample in terms of both demographic and epidemiological characteristics made the extensive analysis uncertain, as there was no normal distribution in all the data. Moving on, some statistically significant correlations were found, both in quantitative and qualitative variables.

The relationship between the diagnosis category according to ICD-10 and the degree of service provided by the Katz Scale was examined. Grouping the diagnoses into F70-F79 (Intellectual Disabilities), F20-F29 (Schizophrenia, schizotypal, and delusional disorders), and other categories, a service requirement pattern in the two most common disorders was demonstrated. As shown in figure 3, most patients with diagnoses in the F70-F79 range required continuous care, in contrast to patients with F20-F29 diagnoses who remained self-sufficient. The chi-square analysis showed a p-value of <0.05.

The chi-square test did not yield statistically significant results for the correlation between most parameters of the "difficult patient" and diagnostic categories. In terms of Perspectives, the medical perspective was not statistically significant (p=0.879). However, the nursing perspective was statistically significant in the chi-square test, with a value of 7.37 and p=0.02 (<0.05).

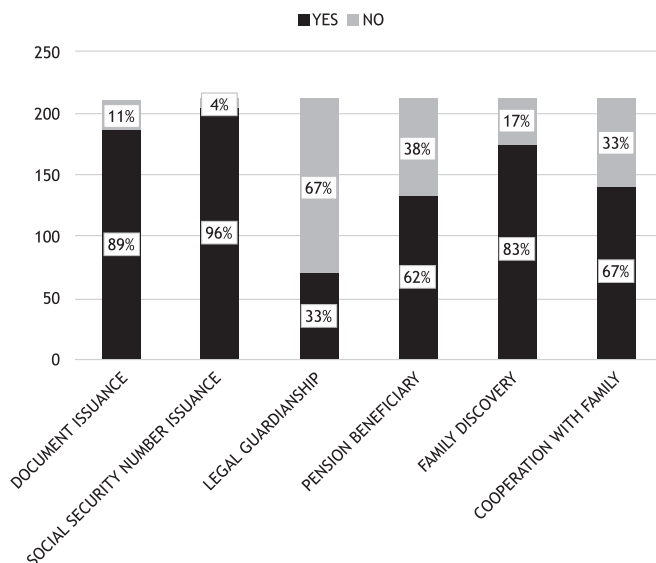


Figure 2. Social service provisions (axes).

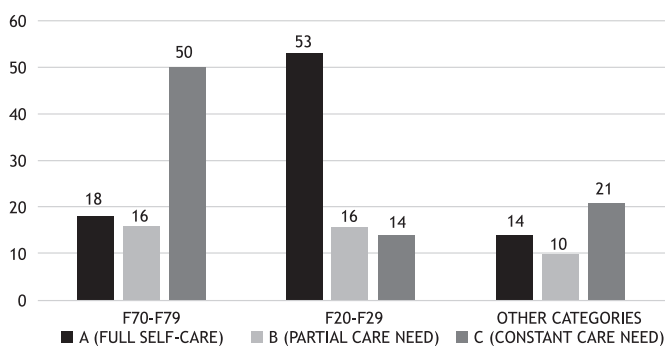


Figure 3. Degree of care distribution per disease category.

One-way ANOVA analysis on the degree of service requirement and the current age of the patients revealed a statistically significant difference (p<0.05). Post hoc analysis indicated that the comparison was statistically significant between the fully self-sufficient patients and those requiring continuous care (p<0.05).

Discussion

The results demonstrate the current position in Greece of the Psychiatric Hospital of Leros as a psychiatric institution. The Institution continues to care for 212 patients in long-stay units, regardless of their type. However, the average age of around 62 years among the patients indicates the aging population of those receiving care. This aging is reflected in both physical comorbidity and frequent hospitalizations in other clinics within the hospital. Continuous and uninterrupted care was required for 40% of the patients, unable to provide self-care at any level.

The main psychiatric diagnoses leading to admission were psychotic disorders and intellectual disability, ac-

counting for 80% of the cumulative diagnoses. However, since 1989, the year of the Psychiatric Reform, new admissions have varied in terms of psychiatric diagnoses. Two-thirds of new admissions fall within the psychotic spectrum, while the second largest category consists of patients with organic mental disorders, particularly various forms of dementia. This difference reflects the different approaches now taken towards patients with neurodevelopmental disorders, as well as the provisions provided in childhood in terms of societal integration.

Another noteworthy point is whether patients are local or not. 40% of the patients were admitted to the Institution because they resided in the South Aegean and not solely to relieve the other psychiatric units in the country. Unfortunately, even to this day, 60% of the hospitalized patients are not local to the South Aegean region, indicating that the Institution still does not fully conform to the modern principles of Community Psychiatry. The patients we care for, from the hospital's history, continue to be living proof of the consequences of the old policy of mass transfers of psychiatric patients to the "asylum of souls" in Leros.

The aging of the hospitalized population has transformed the psychiatric structures of the Psychiatric Hospital into informal psychogeriatric units in terms of medical and nursing practice. The patients at the Institution were largely not considered "difficult patients," but a certain percentage exhibited self- or hetero-destructiveness due to their psychiatric or neurodevelopmental disorders. Before deinstitutionalization, patients were considered "difficult" by default, in a dehumanizing approach to individuals with mental illnesses. However, our results showed a statistically significant correlation between diagnoses and the "nursing perspective," but not the "medical perspective." The nursing staff is called upon to spend long periods with the patients and assist them with all their needs. This intense interaction certainly changes the subjective perception of the patient's "difficulty" property.

The data from the Social Services of the Hospital reflects the interdisciplinary approach followed. The indi-

cators of social service are just one example of the long-standing and multidimensional effort at the Hospital for social work, reintegration into society, and patient empowerment. Specifically, this approach is supported by a team of psychologists from the Social Cooperative Limited Liability Company of the Mental Health Sector of the Dodecanese, as well as other hospital services provided to hospitalized patients.

It is necessary to clarify that patient stays in Psychosocial Rehabilitation Structures usually last for a minimum period of one month, or else patients are admitted to the Acute Department. The main aim of these structures now is to provide care for patients who cannot reside in the community, rather than simply long-term hospitalization and institutionalization.

The limitations of the study are related to the dynamics of the population. Compliance, self-care abilities, or collaboration with the institution and the family environment are fluid and can change in a very short period. Similarly, the number of patients is also variable. The heterogeneity of the sample and the limited availability of data from previous years significantly restricted further research.

In conclusion, the Psychiatric Hospital of Leros, as a regional psychiatric institution, reflects the current image of Greek Psychiatry, both in its positive aspects, with improvements in infrastructure and patient care provisions, as well as its negative aspects. The most significant example for Leros, with its unique history, is the aging of patients and the accompanying aging of staff, with all the implications and difficulties that this entails. At the same time, the institution is called upon to provide mental and physical health services to the refugee and migrant populations, further intensifying existing shortcomings.

Psychiatric reform continues to be applied, as multifaceted as it is and will remain a crucial issue in the future.^{16–19} The current state of the Leros State Psychiatric Hospital provides satisfactory evidence that after all these years, it is no longer Europe's or Greece's dark secret, but rather a mental health institution comparable to other modern European institutions.

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Ερευνητική εργασία

Κρατικό Θεραπευτήριο Λέρου: Μια αποτύπωση της σημερινής πραγματικότητας

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ΠΕΡΙΛΗΨΗ

Η παρούσα μελέτη αφορά στην παρουσίαση των βασικών δημογραφικών και κλινικών χαρακτηριστικών των σημερινών ασθενών, που διαβιούν στις Δομές Ψυχοκοινωνικής Αποκατάστασης του Κρατικού Θεραπευτηρίου Λέρου. Σκοπός της καταγραφής και παρουσίασης είναι η ανάδειξη των συνθηκών βελτίωσης και των δράσεων της Πολιτείας μέσω των προγραμμάτων της αποασυλοποίησης και της κοινοτικής ψυχιατρικής, με βάση τις σύγχρονες κατευθυντήριες οδηγίες. Επιπρόσθετα, προβάλλεται η σημερινή διασύνδεση των Ψυχιατρικών Δομών του Θεραπευτηρίου με τα Τμήματα και τις Κλινικές του Γενικού Νοσοκομείου, ως προς την παροχή υπηρεσιών υγείας στους χρόνιους ασθενείς του Θεραπευτηρίου με βάση το βιοψυχοκοινωνικό πρότυπο και την εφαρμογή του στην ιδιαίτερη περίπτωση της Λέρου. Η πληρέστερη παρουσίαση του προφίλ των ασθενών περιλαμβάνει τόσο υποκειμενικά κριτήρια, όπως την άποψη του προσωπικού για τη συνεργασία του ασθενούς, όσο και αντικειμενικούς παράγοντες, όπως τη συμμόρφωση στην αγωγή και την παρουσία αυτο- ή ετερο-καταστροφικότητας. Παράλληλα, ποσοτικοποιείται και ομαδοποιείται ο βαθμός φροντίδας που απαιτείται για κάθε ασθενή, με βάση τη δυνατότητα αυτοεξυπηρέτησης. Αυτό επιτυγχάνεται με τη χρήση της πρότυπης σταθμισμένης κλίμακας του Katz για τις βασικές δραστηριότητες της καθημερινής ζωής. Επίσης, παρουσιάζονται οι βασικές δράσεις και παροχές προς τους ασθενείς, σε επίπεδο κοινωνικών υπηρεσιών και διασύνδεσης με την κοινωνία, η ύπαρξη ή μη σταθερής επαφής με συγγενικά πρόσωπα και συνεργασίας με αυτά, για ζητήματα που αφορούν στην υγεία και περίθαλψη των ασθενών. Επιγραμματικά, οι σημερινοί ασθενείς, συνολικά 212, έχουν μέση ηλικία τα 62,4 έτη (τυπική απόκλιση $\pm 13,6$ έτη). Η μεγαλύτερη συνεχής νοσηλεία στο ίδρυμα είναι 62 συναπτά έτη. Από την έναρξη της Ψυχιατρικής Μεταρρύθμισης το 1989 υπήρξαν 87 εισαγωγές από την κοινότητα, με τόπο καταγωγής στο 85,1% το Νότιο Αιγαίο, ακολουθώντας σε μεγάλο βαθμό την αρχή της εντοπιότητας των ασθενών. Η νοητική υστέρηση και διαταραχές του ψυχωτικού φάσματος αποτελούν τις πιο συχνές διαγνώσεις εισαγωγής, συνολικά με ποσοστό περίπου 40% για κάθε διαταραχή. Σχετικά με τους 87 ασθενείς που νοσηλεύτηκαν μετά το 1989, οι διαταραχές ψυχωτικού φάσματος ήταν διαγνωσμένες στη μεγάλη πλειοψηφία (58 ασθενείς, 66,7%) ακολουθούμενες από τις οργανικές ψυχικές διαταραχές (10 ασθενείς, 11,5%). Οι λοιποί ασθενείς έπασχαν από άλλες διαταραχές. Η σωματική συννοσηρότητα, η ανάγκη φροντίδας και εξυπηρέτησης, ιδίως στους ασθενείς με νοητική υστέρηση, δείχνουν το πώς έχει αλλάξει ο χαρακτήρας του Ιδρύματος και πλέον σε μεγάλο βαθμό παρέχει ψυχογηριατρική περίθαλψη. Συμπερασματικά, σκοπός της παρούσας έρευνας είναι η ανάδειξη του σημερινού Κρατικού Θεραπευτηρίου Λέρου, η εικόνα του οποίου διαφέρει από αυτή που έχει αποκρυσταλλωθεί στερεοτυπικά από το παρελθόν, τόσο στην ερευνητική κοινότητα όσο και στον γενικό πληθυσμό.

ΛΕΞΕΙΣ ΕΥΡΕΤΗΡΙΟΥ: Ψυχιατρική μεταρρύθμιση, Λέρος, ψυχιατρική, αποασυλοποίηση.