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Descriptive study of evolution experienced by users of mental health residence, after 10 years of operation

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Introduction. The transformation of the social-health benefits system must demonstrate efficiency. The objective of the current work is to evaluate the evolution of those living in a residence during the first 10 years of its operation.

Method. Of the 205 patients used in the assessment, 93 were admitted. The evolutionary study was done with the 62 patients that were cared for between 2002-2012. The variables studied include the ENAR-CPB Scale, days hospitalized, community activities, a satisfaction survey and QOL.

Results. After the assessment process only 45% of those proposed for admission were actually admitted. Resident rotation is 3.4% annually. Many leave the program after being referred to a long-term psychiatric hospital; 14.5% leave the residence in order to have a more autonomous life.

After living 2 years in the residence there is a general improvement in the majority of residents, which is maintained after 5 years as well. This improvement is maintained even after 10 years, however a general loss of capacities is experienced.

Conclusions. Living in a Residence favors improvement in the quality of life, both subjectively as well as objectively.

Institutional treatment consists of working with the patients in a way that treats them as individuals, so they can go about their lives and perform their tasks with creativity. In order for this to be possible, an individualized and flexible model is required.

Keywords: Severe Mental Illness, Residence Program, Evaluation Functionality

Actas Esp Psiquiatr 2018;46(1):12-20

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Estudio descriptivo de la evolución experimentada por los usuarios de una residencia de salud mental, tras 10 años de funcionamiento

Introducción. La transformación del sistema de prestaciones socio-sanitarias tiene que demostrar eficiencia. El objetivo de este trabajo es evaluar la evolución de los residentes atendidos en una residencia durante sus primeros 10 YEARs de funcionamiento.

Método. De 205 personas que optaron por plaza de residencia, 93 fueron admitidos. El estudio evolutivo se realiza con 62 pacientes atendidos entre 2002-2012. Las variables estudiadas incluyen la Escala ENAR-CPB, días de hospitalización, actividades comunitarias, encuesta de satisfacción y QOL.

Resultados. Tras el proceso de valoración sólo ingresan un 45% de los usuarios propuestos. La rotación de residentes es del 3,4% anual, siendo la derivación a un recurso de hospitalización psiquiátrica de larga estancia la mayor causa de baja del programa. El 14,5%, en cambio, deja la residencia por un proyecto de vida más autónomo.

A los 2 años de ingreso la mejoría es mayoritaria, a los 5 se mantiene y a los 10 se produce una pérdida general de capacidades, pero manteniéndose una mejoría respecto al momento del ingreso.

Conclusiones. Vivir en una residencia favorece la mejoría en la calidad de vida de los residentes; tanto subjetiva como objetivamente.

El tratamiento institucional consiste en ir trabajando con los usuarios y negociar desde su singularidad el modo de que no se sometan y puedan ejecutar creativamente su tarea. Para ello es necesario un modelo de intervención individualizado y flexible.

Palabras clave: Trastorno Mental Grave, Programa Residencia, Valoración Funcionalidad

INTRODUCTION

In some cases, in severe pathologies like schizophrenia, a person's progressive deterioration may condition one's life in terms of chronicity. Given this, it is not uncommon that these individuals show high vulnerability unto stress, have insufficient skills for performing daily activities, and experience difficulties in their social relationships, resulting in social isolation, poverty, repeated hospitalisations or even homelessness.

Currently, the evolution of schizophrenia is considered to result of the intervention of interrelated variables, in which the social factor occupies a relevant position. Bachrach[1] proposes that disability in the mentally ill is based on three spheres: primary, referring to the defect caused by the symptoms inherent to the illness itself; secondary, referring to the handicaps or "adverse personal reactions" associated with the experience of the illness; and tertiary, derived of societal response to the illness.

In recent years, psychiatric care has focused on short-term symptomatic treatment, and relegated long-term clinical treatment, repercussions and chronicity to the social system.[2] The WHO, in its 2001 Mental Health Report, draws attention to the fact that "reducing the approach of healthcare to symptomatic treatment, while failing to approach the disability and its deficiency syndrome, curtails the rights of individuals to receive comprehensive treatment for their illnesses and contributes to their chronification, stigmatization and risk of marginalisation."[3] Current evidence seems to confirm the possible recovery of patients if treatment comprised of global, well-coordinated and ongoing services is provided in the long term.[4]

The creation of living spaces for persons with serious mental illness (SMI) and the possibility of keeping them within their usual living environments is an important factor in consolidating community mental health (MH) services. The main goal is to foster the residents' permanence and participation in social life, by covering their basic, vital necessities, like housing, maintenance, and certain basic healthcare needs (personal hygiene, self-care, taking of medication, daily living activities (DLA), etc.), significant interpersonal relationships and institutional support during stressful situations.

Residences must be considered a place for psychosocial rehabilitation of persons with SMI, focused on the interaction between the individual and the context, and activate the individual's personal resources.[5] Its function must go beyond that of an asylum.[6] Therefore, they should contemplate aspects like the flexibility of support, users' decision-making capacity, their participation in collective organisation and, in general, something that is difficult to specify and measure: what we refer to as "cosiness".

Rehabilitation in residences is based on "in vivo" learning of useful behaviours for community living and on relational experience. These are its differentiating features, compared with conventional psychiatric treatment (oriented toward reducing positive symptoms and focused on disabilities).

Those defects that were attributed to former mental asylums prior to the psychiatric reforms of the 70s and 80s, namely massification, depersonalisation and social isolation, are errors that may be reproduced in residences if certain aspects are overlooked, such as the building's structure, number of residents, personnel, management mechanisms, dynamics of its internal procedures, restrictiveness of rules, and mechanisms for participation in its overall operation.

At a crucial time in the transformation of the social and healthcare benefits system, it is necessary to demonstrate the efficiency of residences and the improvement in quality of life of its residents. Over a decade of residences in operation in Spain has contributed cumulative evidence on the usefulness of these resources for improving rehabilitation of persons with SMI[7-9] with regards to clinical stability, social networks, quality of life, users' level of satisfaction and personal and social functioning, even if only through *in vivo* learning of useful behaviours for community living.

This study evaluates the progress of residents cared for at the "Roger de Lluria" residence (Mental Health Foundation CPB) over its first 10 years in operation (2002-2012), using as indicators the use of healthcare resources, psychosocial functioning and autonomous living, as well as users' personal satisfaction.

METHOD

Between 2001 and 2012, a total of 205 individuals were proposed for admission in the residence by the Department of Social Affairs and Family of the regional government of Catalonia. Of the 205 patients proposed, only 93 were admitted for residential living. Biographical data (age, gender, psychiatric diagnosis and place of residence prior to admission) was extracted for these 93 residents between 2002-2012, and withdrawals from the program were analysed calculating the length of stay in months and associating causes of withdrawal with psychiatric diagnosis.

This evolutionary study is based on an initial sample of 62 users, the number of individuals who had been living in the residence for at least two years. Variations are taken into account as detected in the ENAR-CPG Scale[10] (at admission and at 2, 5 and 10 years). To define the concepts of the sam-

ple's improvement or worsening, a comparison is made of the average values for the total and by subscales, taking into account the length of stay in the residence. The change percentage between the values is also calculated (*considering that: over 25% is a highly satisfactory improvement; 10-25% is a reasonable improvement; +10% means no significant change; and below 10% means that the resident has worsened).*

Days of psychiatric hospitalisation per resident are collected according to years of stay in the residence as of the year prior to admission, and the average is calculated (in days of admission) per year. Data is also collected on external activities in which the residents participate, and their weekly hours of dedication to these. To calculate the coefficient for integration in the community, the type of resource used (with a value between 1-4, depending on the normalisation level), timetable (hours/week) and level of compliance (with a value between 0-3) are considered.

The residents complete an anonymous service satisfaction survey each year, designed by the Mental Health Foundation CPB (residence manager) itself. From this survey, we extract the values referring to those aspects they consider have changed since admission to the residence as regards clinical stability, quality of life, autonomy and responsibility in acquiring health-related habits and greater capacity for assuming DLA. Residents also completed the Quality of Life (QOL) scale[11,12] at 2 and 5 years of stay at the residence.

IBM-SPSS v.19 software was used for statistical analysis, and the descriptive statistics for the studied variables were evaluated, using parametric statistical tests and the t-test for continuous variables.

ANALYSIS OF THE RESULTS

Of the 205 patients proposed, only 93 were admitted for residential living. Figure 1 depicts the evaluation process and the grounds for which the candidates finally do not complete the residence admission process. It is worth highlighting that over half of the users are not admitted; only 45% of the proposals result in admission. Of the users, 30% fail to even initiate the evaluation process, 16% do not fit the resident user profile and 9% in the end do not complete the admission process, despite admission having been evaluated as a possibility.

Table 1 describes the sample's socio-demographic and clinical characteristics.

Resident rotation is 3.4% annually, with derivation to a long-term psychiatric hospitalisation resource the leading

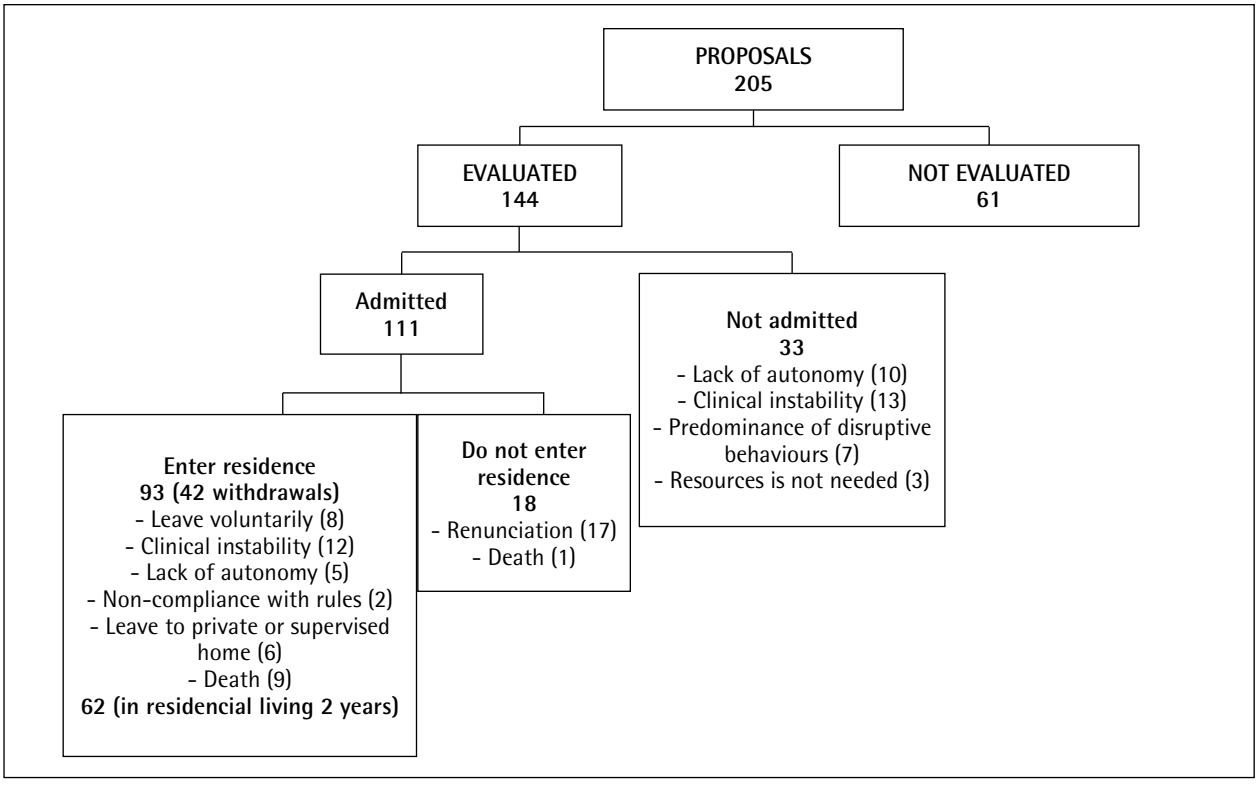

Figure 1 | *Data from the candidate evaluation process*

Table 1	Sociodemographic and diagnostic-related data
Gender and Ange	
Males	70 %
Female	30 %
Average age	44.5 years (SD: 7.7)
Main Diagnosis	
Psychotic disorder	81.7 %
Affective disorder	6.5 %
Personality disorder	3.2 %
Other	8.6 %
Level of studies	
Without studies	24.7 %
Primary school	49.5 %
Vocational training	7.5 %
High school	17.2 %
University	1.1 %
Home place of the residents (defined as the usual living place prior to admission at the residence)	
Private home	60 %
Homes with support personnel	4.5 %
Transfer from another residence	16 %
Social Services centre	6.5 %
Hospitalisation (long-term hospitalisation, over 200 days)	13 %

cause of withdrawal from the program (28.5%), followed by death (21.5%) and derivations to high dependency healthcare units (12%). Those users who left the residence in pursuit of independent living represent 14.5% of the total, and had a 5-year average stay in the residence. These data manifest the difficulty inherent to externalising users. It must also be mentioned that 100% of the users diagnosed with Personality Disorder (n=) were withdrawn (due to non-compliance with the rules or derivation to high-dependency psychiatric care), with an average stay at the residence of 2.5 years.

Improvement of clinical stability is observed in a reduction of 18%, as the change percentage, between the values of the "clinical stability" sub-scale of the ENAR-CPB scale, before admission to the residence and the two years prior to that; as well, a reduction in the length of stay (from 8,915 to 704 days), also with a reduction in the number of individuals requiring hospitalisation, from 43 to 10 residents. (Figure 2).

This clinical improvement is maintained over time but, as of the sixth year, a trend appears with regards to an increase in the length of stay (average per patient): 6.8 in the fifth year, 9.6 in the sixth, etc., until reaching 14.1 in the tenth.

Upon reaching the tenth year of stay in the residence, the improvement in clinical stability (ENAR-CPB) represents only 2.4% as the change percentage compared with the value at admission to the residence. This fact correlates with the fact that withdrawals due to derivation to a long-term psychiatric care facility mostly occur between the 6th and 8th years as of admission, with an average of 4.5 years as of admission.

The same vision results when comparing the use of community rehabilitation resources (Figure 3). A progressive increase is observed the initial 4 years, with stabilisation (downward) the 4 subsequent years, and a significant drop the 2 following. The most-used resources are the Day Centre and the Social Club (by 60% of residents). Recreational/leisure and learning activities (courses, sports, associationism, volunteering, etc.) are used by 43% of the residents. Though without continuity, 19% of users took part in pre-employment activities. Furthermore, though there is currently a significant drop in socio-labour integration, 11% of the residents had obtained employment.

According to the index measuring integration in the community, most of the resident experience very reduced community participation linked to MH resources. Only 8% have an acceptable level of integration in the community and 10% do not participate in external activities, increasing to

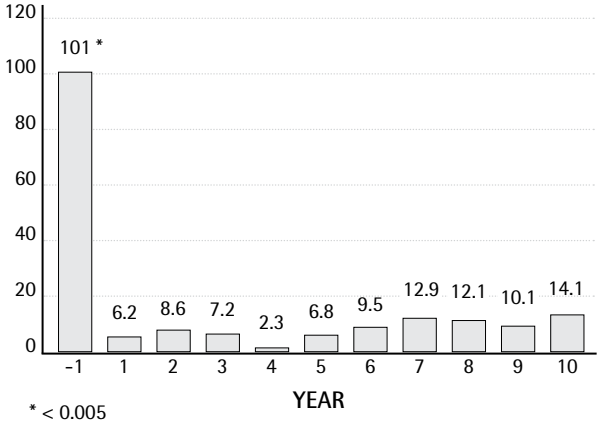

Figure 2 | *Days of psychiatric hospitalisation (average) according to years of stay in the residence*

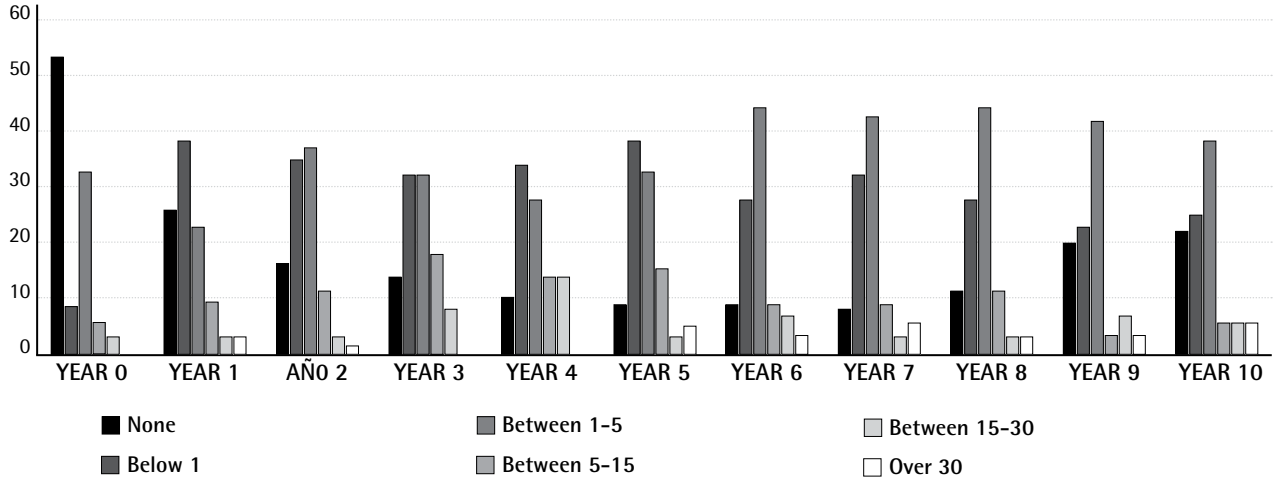

Figure 3 | *Community insertion, in percentage according to years in the residence*

20% during the tenth year of residential living. Prior to admission to the residence, 61% had no activity at all, or did not achieve continuity with any resource. After admission, this value dropped to 48%. Participation in MH resources increased from 5% to 11%. Despite an overall improvement, 18% of the residents experienced a reduction in their integration in the community, especially in the case of individuals who attended the Day Centre, who after admission to residential living did not successfully engage in the new resource.

In the residence (in accordance with the first section of the community integration sub-scale of the ENAR-CPB scale), there are 4 differentiated groups according to their usual daily occupation: a first group displayed good engagement in external resources which kept it occupied a minimum of 25 hours/week (23%); another group is occupied between 10-20 hours/week (16%); a third group has irregular participation or is occupied less than 10 hours/week (38%); and, the last group does not engage in any external activity at all, or participation is almost non-existent (23%).

Using the ENAR-CPB scale as reference, it is observed that at 2 years after admission, most users experience an overall improvement (72.5% of residents), though a small group (1.6%) worsens. This overall improvement also results in the 6 sections: clinical stability (representing an improvement of 18%), healthcare (improvement of 4.2%), DLA (improvement of 11.7%), autonomy and self-governance (improvement of 5.2%), interpersonal relationships (improvement of 6.1%) and community integration (improvement of 8.8%) (Figure 4).

The group of residents that reflects the greatest improvement is that which came from a psychiatric hospital

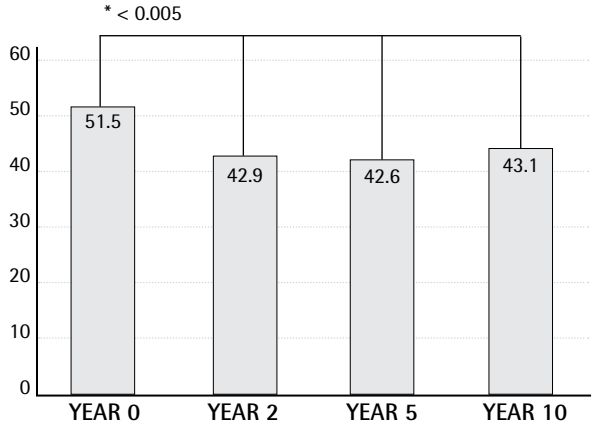

Figure 4 | *Change, according to progress on the ENAR-CPB scale*

(improvement of 12%) and private homes (improvement of 11%). For those users who came from another residence, improvement is quite reduced (improvement of 4.7%, not significant for 75%). For those users from homes with support personnel or homes belonging to Social Services, the improvement is quite similar (improvement of 3.5%).

A positive trend is maintained at 5 years as of admission (with improvement compared with the situation prior to admission for 76.1%, with a change percentage of 11.1%). This overall improvement also occurs in almost all of the sections: healthcare (improvement of 5.7%, 1.6 points higher than year 2), DLA (improvement of 20.7%, 9 points higher than year 2), autonomy and self-governance (improvement of 57.1%, 1.9 points higher than year 2), interpersonal rela-

tionships (improvement of 7.8%, 1.7 points higher than year 2); though two demonstrate a slight downward trend: clinical stability (representing an improvement of 17.4%, 0.6 points lower than year 2), and community integration (representing an improvement of 8.6%, 0.2 points lower than year 2). At 5 years as of admission, 8.7% of the residents worsen, compared with their initial status.

At 10 years of residential living, an overall loss of capacities is observed in 9.5% of the residents. By subsections, an upward trend is maintained in healthcare (improvement from 5.7% to 6.6%), autonomy (from 7.1% to 5.7%) and in interpersonal relationships (from 7.8% to 11.9%). A slight downward trend is observed in two sections, though maintaining the improvement, compared with 2 years as of admission: clinical stability (drop in improvement from 11.1% to 10.6%) and DLA (drop in improvement from 20.7% to 20.2%). A significant drop is observed only for community integration (drop in improvement from 8.6% to 2.1%). Despite this downward trend, the overall improvement compared with the time of admission is maintained in 76.2% of users.

This improvement is interpreted as even greater when taking into account the subjective perspective of the resident, who considers (in accordance with the satisfaction survey completed at 2, 5 and 10 years as of admission to the residence) that clinical stability has improved by 85-81-76%, respectively; autonomy and responsibility, by 81-85-85%; acquisition of health-related habits and capacity for assuming DLA, by 81-71-66%; and quality of life, by 81-76-81% (Figure 5).

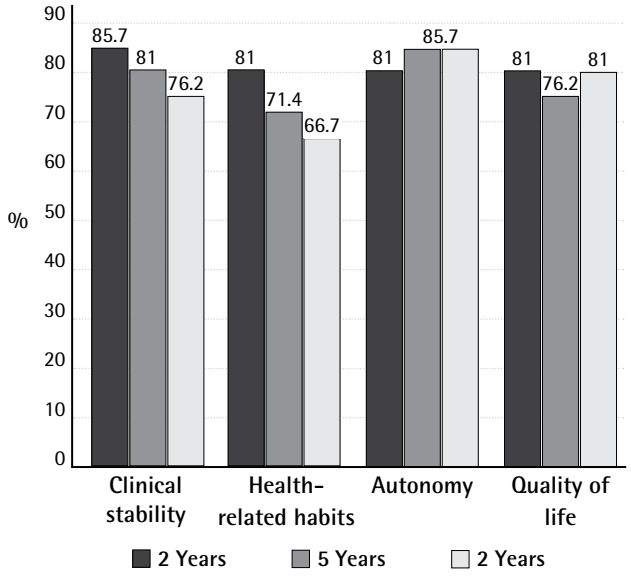

Figure 5 — *Subjective appreciation of improvement, in percentage according to years in the residence*

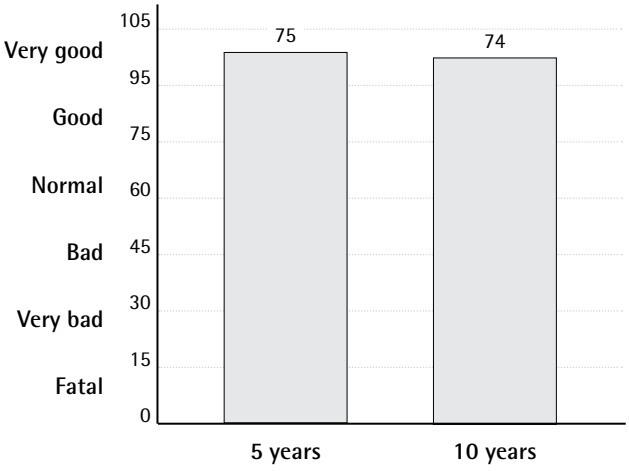

Figure 6 — *Quality of life according to the QOL scale*

Along the same lines, the Quality of Life (QOL) scale, completed at 5 and 10 years as of admission to the residence, resulting in a noteworthy quality of life (75 and 74, respectively of 105, with a SD of 0.6 and 0.4) (Figure 6).

CONCLUSIONS

This study's results confirm the fact that residential living for individuals with SMI favours their quality of life, both from objective perspectives (fewer psychiatric hospitalisations, participation in community living and rehabilitation activities, improved functioning in DLA, and clinical stability) and subjective perspectives (self-perceived improvement in clinical stability, quality of life, autonomy and acquired health-related habits).

Two indicators reflect the improvement in clinical stability: a reduction of 18%, as the change percentage, between the values of the "clinical stability" sub-scale of the ENAR-CPB scale, before admission to the residence and the two years prior to that, and a drastic reduction in the length of stay for those same periods, and a reduction in the number of individuals requiring hospitalisation. A greater usage of community rehabilitation resources is observed, with a gradual increase over the initial 4 years; the Day Centre and Social Club are used the most. Participation in community living also improves, reflected in an increase of the community integration index, though low levels are common. After two years of residential living, this index drops from 1.6 to 3 points. Prior to admission to the residence, 61% had no activity at all, or did not achieve continuity with any resource. After admission, this value dropped to 48%.

The residents also have a subjective appreciation of this improvement, and they consider to have experienced improvement in clinical stability, autonomy and responsibility, acquisition of health-related habits, capacity for assuming DLA, and quality of life, between 81-76-81%.

It may be affirmed that residential living entails a substantial modification to the structure of daily activities, relational aspects, rehabilitation, and higher clinical stability. To evaluate real change variables, we have considered the study by RP Liberman and A Kopelwicz: "an empirical approach to recovery from schizophrenia". From this study, we highlight 6 of the 10 given factors that undergo change upon admission to residential living. 1. Family factors (with regards to the relational environment, considering the residence a "substitute family").[13,14] 2. Adhesion to treatment.[15,16] 3. Therapy as support, through a collaborative therapeutic alliance.[17,18] 4. Positive neurocognitive functioning.[19-21] 5. Absence of deficiency syndrome.[22] 6. Access to a global, coordinated and ongoing treatment.[23,24]

The importance of institutional treatment in residential resources is critical, given that the subject and the institution establish a paradoxical relationship characterised by the search for autonomy, but also by the need for dependence. In this relationship, it is usual for a trend of standardising care to occur, depending on the users' individual characteristics and the difficulties inherent to adapting to the residents' needs. This attempt to standardise is reinforced by the need for control, and the higher the number of users, the greater the standardisation.

René Kaës[25] had previously described the existing dynamic interaction between psychotic structure and institutional response: life in an asylum complicates the course of psychosis to the extent that the caregivers unconsciously organise themselves according to their patients' psychic conflicts. Institutions promote collectively organised forms of response unto the mass transfer of patients and given the concerns that these raise in caretakers.

Bleger described the way in which psychiatric institutions tend to adapt and organise themselves according to the pathology and, contrary to their function of attending to the mental pathology, thereby maintain and perpetuate it.[26]

Miller and Keys[27] highlight the way in which excessive rules, together with the notorious institutionalisation, also provoke the sensation that patients are not trusted by others and are not entitled to control their own lives.

This causes patients to react with helplessness, submission and lack of initiative, resulting in situations of dependency and attitudes of conformity (by both parties: residents and professionals), and reinforcing the continuity of stereotypical, impoverished behaviours. Over time and with regards to the improvement seen during the initial years of residential living, the residents tend to regress.

The institutional approach consists of working with the users and negotiating, from each resident's singularity, a way to keep them from subservience and encouraging them to creatively carry out their activities. It is necessary to promote an individualised and flexible intervention model that entails the resident's participation. For the residence to be therapeutic, the emergence and expression of conflict must be allowed so that changes will occur to modify the initial situation. It is important to establish effective and professional ties with the residents so that they will feel listened to and cared for, and consider that the professionals effectively take an interest in their problems and are committed to helping them.

The challenge is to define the optimum distance, avoiding over-protectiveness (which causes feelings of intrusion and anxiety from excessive attachment) as well as undue aloofness (which fosters feelings of abandonment). "The best way for someone to feel well is to be able to express one's emotions and feelings to another person he or she feels is understanding, and to feel valued by others. That's the point, precisely, of the organisation of residential living. It is a setting that best predisposes the residents to start working toward achieving their goals of autonomy and integration. The intention is to facilitate the residents' emotional expression as a way for achieving their psychological well-being and mutually supporting one another".[28]

In general, the progress of most residents is satisfactory, as this study reflects. However, the types of users that withdraw are clear evidence of different groups of residents, with significant difficulties adapting. A first subgroup presents a range of combined, serious symptoms: disruptive behaviours (not necessarily violent, but that disturb coexistence) and ongoing difficulties in their relating with different community mechanisms and in the residence. They present psychopathic and functional traits that, because they generate serious conflicts for coexistence, impede their care in a residential setting. The full 100% of BPD patients withdrew from the resource. Another subgroup comprises psychotic patients with unstable symptoms; they have serious difficulties remaining within a residential setting and function better in less socially-demanding environments that provide them more options for refraining from social interaction. This problem is difficult to identify during the admission evaluation process, and the challenge of adapting to an open resource that demands relating with others only becomes apparent after months, or even years, have passed (King & Shepherd, 1994).[29] Most of the residents who withdraw from the residence to go to a High Dependency Unit (HDU) are referred, on average, 3 years after admission

(reaching up to 8 years). A third group comprises those individuals with important, associated pathological symptoms which, together with the low level of autonomy for personal self-care, results in higher dependency on healthcare. These cases represent 12% of withdrawals, to which we must include the 21.5% of deaths (all due to natural causes).

If insufficient housing options and residential services are available in the community, many of the efforts for rehabilitating and integrating persons with SMI may be seriously curtailed. The articulation of a community services network for attending to and integrating these individuals, in the most normalised way possible, must prioritise and organise the proper coverage of their needs for housing and residential care.[30]

A diversity of resources is required to address the need of a living space for persons with SMI; this diversity must be adapted to each individual's different situations and support-related needs, considering socio-economic conditions, capacities and level of autonomy in performing DLA.[31]

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