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# Transition from institutional care to community care for residents of community care units in Greece: Construction of the notion of "asylum" in community care units

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#### **Abstract**

The research study presented in this article (based on my PhD dissertation), aimed to explore the shifting meaning of "asylum" for people with severe mental illness (SMI), who are residents of community care units (CCUs), by comparing and contrasting participants' experiences of CCUs with their previous lives in institutions. Currently, there is a gap in the Greek context in the field of qualitative studies exploring the issues of deinstitutionalisation and community care based on residents' and staff members' experiences. Semi-structured interviews were conducted with residents (N=35) and staff members (N=20) of four CCUs run by Klimaka (a non-governmental organisation) in Attica, the legal advisor of Klimaka, two mental health officers, a psychologist and a psychiatrist from Dromokaition Mental Health Hospital. Data were analysed thematically. Most residents felt that institutions provided a "temporary asylum" based on: 1) financial security; 2) stress-free daily routine; 3) segregation from the pressures of the outside world; 4) good or neutral relationships with staff; and 5) trust in their treatment. But most felt that the hospital had never become their actual home. All residents felt that CCUs offered them a temporary or permanent asylum, based on: 1) financial security; 2) enriched daily routine; 3) wider social networks; 4) an increased degree of freedom; 5) good relationships with staff; 6) trust in treatment, with increased awareness; and 7) absence of abuse. Twelve residents felt that the CCU was their permanent residence, while for seven of them it was a temporary one, before moving to more autonomous living conditions. The study concludes that "Asylum" does not represent a physical entity, but a set of interrelated criteria which, if met by services, can be achieved for people with SMI anywhere.

#### **Keywords**

Deinstitutionalization, Severe Mental Illness, Community Care Units, Community Care, Mental Health Institutions, Asylum

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#### Introduction

The research study presented in this article (based on my PhD dissertation) (1) in the field of Psychiatry, dealt with the issue of deinstitutionalisation and transition to community care of individuals experiencing SMI, who have been deinstitutionalised from public mental health hospitals to community care units, run by Klimaka, a private, non-profit organisation in Athens, Greece. In this research, all residents and staff members of four community care units that Klimaka runs in the greater area of Athens were interviewed. In order to get a more complete picture on deinstitutionalisation of patients with SMI in Greece, the legal advisor of Klimaka, two staff members of Dromokaition Mental Health Hospital and two officers from the Greek Ministry of Health responsible for mental health services were also interviewed.

The first aim of this study was to explore the shifting meaning of "asylum" by privileging the voices of residents. The research aimed to discover what contributes to residents' notion of "asylum" in the community care unit: while one dimension of "asylum" is that of a place offering **shelter**, **safety** and **security**, it is important to discover what particular aspects of residents' everyday life in the community care unit offer this sense of safety and security, and what do not.

A second aim of the study was to compare and contrast residents' life in the community care unit with their previous life in the mental health institution. This way, it became possible to discover which particular aspects of residents' everyday life in the hospital used to offer this sense of safety and security, and which ones did not. Residents got a chance to compare and contrast, express their living preferences, and describe the changes that their placement in the community care unit has brought to their lives.

A third aim of the study was to identify what positive features of asylum might be recreated in the community, and what negative ones need to be avoided; also, what positive features of the notion of "asylum" in the community care unit need to be recreated on a larger scale in the community and what negative ones need to be avoided. Identifying these features can facilitate a better understanding of residents' deinstitutionalisation experience. This understanding can offer valuable lessons of what factors and support mechanisms facilitate a successful transition to community care and what contribute to an unsuccessful one. This way, policy makers can find out what really works for residents of CCUs and reorganise community care services in order to offer true "asylum" to them.

In the Greek context there are very few studies of deinstitutionalisation. Those that do exist tend to focus only on staff or family carers, by using qualitative methods (2, 3), or focus on experiences of ex-patients in the community only, but with the use of quantitative methods (4). In the Greek context there is only one qualitative study with a "before and after" deinstitutionalisation approach (5). Although the study offered valuable insights on the issue of deinstitutionalisation, it was limited by the fact that out of the original sample of 24 chronic patients from a public mental health institution, only 3 individuals had a successful transition to life in a community care unit at the time of the second interview (6-12 months after deinstitutionalisation) (5). This meant that only they were in a position to talk about their life in a community care unit (5). As a result, this was the very first time that a qualitative study explored on a larger scale the notion of "asylum" of residents in a community care unit run by the private sector, and gave at the same time the opportunity to participants to compare and contrast life in the community with their previous life in a mental health institution.

The originality of this research lied in its context (studying transition to community care in Greece), in its setting (units run by the private sector), and in its methodological approach. This research (1) sought to make a serious contribution to knowledge, by filling the gap that exists in the Greek context in the field of qualitative studies exploring the issues of deinstitutionalisation and care in the community, based on **residents' experiences**. This study aimed to fill this gap in knowledge, by providing valuable information on residents' notion of "asylum" in a community care unit, in order to successfully recreate it on a larger scale in the community.

This research also serves an international trend for the production of knowledge – evident also in the U.K. Department of Health's Research and Development strategy – which can be understood as "...moving away from the traditional, university—based model of knowledge production towards a new one", that places – among other groups – patients at the center of research (6).

As far as the group of Klimaka's residents that participated in this study is concerned, it should be mentioned that they have all been involuntary patients in public mental health institutions. A few had also been hospitalised for brief periods of time in private mental health hospitals as well. All residents of Klimaka according to the Greek Law, were involuntarily admitted to mental health institutions, after being examined by at least two psychiatrists, according to the diagnostic criteria used at the time of the involuntary commitment, based on DSM-II, DSM-III, DSM-IV, and DSM-5 (7). All residents at Klimaka's CCUs had experienced a form of psychosis such as schizophrenia or bipolar disorder at the time they were hospitalised and - according to the staff members of Klimaka and some residents' own accounts - they were still receiving medication for schizophrenia or bipolar disorder at the time of the interviews.

#### Theoretical background of the research: Construction of the notion of "asylum" in the community through the exploration of Thirdspace

One of the main reasons why deinstitutionalisation has faced many problems in the U.S.A., U.K., Italy and Greece [among many countries] is that policy makers did not manage to take into consideration the views of mental health service users from the beginning (5). This resulted – in many cases – in community care services not offering true "asylum", but rather offering just similar medical services to mental health hospitals, but

in a different setting. However, if we want community care services to work, and avoid a turn to reinstitutionalisation, neoinstitutionalisation, transinstitutionalisation, incarceration to prisons, homelessness or recreation of the total institution, it is our duty to explore ex-patients' notion of "asylum" and work hard in order to recreate it in the community.

In order to do so, we need to explore residents' of CCUs views and try to gain a knowledge which has been previously systematically hidden from mainstream human awareness and realisation; this is a "non-traditional" knowledge. Ex-patients in general and residents of CCUs in particular, in the Greek context, usually find themselves in the margins of society and if we want to have a clear picture of their views we need to explore their lived experience in the margins of society – or as Edward Soja defines it: the Thirdspace. Edward Soja, in his book: Thirdspace: Journeys to Los Angeles and Other Real and Imagined Places offers a new way of thinking about space, with a deep concern for human welfare being at the heart of his work.

Edward Soja was a Distinguished Professor Emeritus of Urban Planning at UCLA, in the U.S.A. He also taught courses in urban political economy and planning theory. Soja's work *Thirdspace* offers new ways of thinking about space: Soja is particularly interested in the way issues of class, race, gender and sexuality intersect with what he calls the spatiality of social life, and with the new cultural politics of difference and identity this generates (8).

Edward Soja's main objective in his book *Thirdspace* is to encourage the readers to "...think differently about the meanings and significance of space and those related concepts that compose and comprise the inherent *spatiality of human life:* place, location, locality, landscape, environment, home, city, region, territory and geography" (8, pg. 1). Soja believes that in order for us to achieve a better understanding of our contemporary life worlds at all scales, it is absolutely necessary to be strategically aware of our collectively created spatiality and its social consequences (9).

Soja, evolved his own trialectic concerning space: Soja's Firstspace is the material, physical space that can be empirically measurable (8, pg. 66). The physical space and actual building of an asylum or community care unit with rooms, walls, and facilities, for example, can be considered as Firstspace.

Soja's Secondspace is the space that is interpreted, mapped and controlled, and it represents the idealistic background on the basis of which the Firstspace is created. This mental space is tied to the relations of production, and particularly to the order or design that it imposes (8, pg. 67). This is the "dominating" space of regulatory and "ruly" discourse, and thus the representation of power and ideology, of surveillance and control (8, pg. 67). For example, the physical space (Firstspace) of asylum or community care unit is created according to some sort of idealism (Secondspace). The ideology (Secondspace) and the product of ideology (Firstspace) are not always distinct; these two spaces tend to collapse into each other (8).

Sojas' Thirdspace is linked to the underground side of social life (8, pg. 68). Thirdspace is a strategic location, from which to understand and potentially transform all spaces si-

multaneously. It is the space of "lived experience" and "marginality", but also the chosen space for "...struggle, liberation, emancipation" (8, pg.68). For example, Thirdspace represents the lived experience of individuals with SMI in mental health institutions or community care units.

According to Soja, Thirdspace is located in the margins of society, and the invaluable knowledge people gain from exploring the Thirdspace guides their search for emancipatory change and freedom from domination. Thirdspace is of critical importance for this particular research, because most CCUs' residents find themselves in the margins of society, the Thirdspace. In order to have a clear picture of residents' of CCUs views, the margin needs to be explored, and through the knowledge that is gained a better understanding of their notion of "asylum" as a place offering safety and security can be achieved.

In order to explore patients' views, there is a growing requirement for more patient-centred research, exploring perceptions of quality of services (10). This is even more urgent for people with SMI, where patient involvement in research can help policy makers to identify gaps in the service and modify practice accordingly (11). This exploration of the "lived experiences" of residents of CCUs is exactly the focus of this research. This notion of exploring the Thirdspace, is a way of giving to residents a "loud voice" that can influence not only their lives but hopefully future mental health policy as well. Through research like this study, the "margin" gets a chance to speak back to the "center" and to press for beneficial changes in the field of mental health policy.

#### Methodology of the research

#### Sampling Issues

One of the most critical decisions in a qualitative study is whom to include in the sample; as a result, sampling is a key aspect of social inquiry. Participant sampling in qualitative research has to follow a well-defined rationale and fulfill a specific purpose, which is why qualitative sampling is often called purposive (12). In short, purposive sampling refers to the process of selecting participants who serve a specific purpose that is consistent with a study's main objective (12). As Ritchie et al (13, pg. 78) indicate, in purposive sampling "...The sample units are chosen because they have particular features or characteristics which will enable detailed exploration and understanding of the central themes and puzzles which the researcher wishes to study".

A particular purposive sampling strategy is criterion sampling, where all cases that meet some predetermined criteria are studied, and this sampling strategy is very commonly used in studies that explore issues relating to quality improvement (14). In this particular research, the sample was purposive in that all residents had the experience of deinstitutionalisation and transition to community care. The criterion was that all participants resided or worked in community care units for people with SMI, run by Klimaka – a private, non-profit organisation – and were located in the greater area of the city of Athens.

Another important decision in qualitative research is not only *who* will be taking part in a study, but also *how many* individuals will be participating. The trade-off between breadth and depth in a research study affects the size of a sample. The aim of qualitative research is not to identify a statistically representative set of respondents or to produce numerical predictions, but rather to yield detailed and holistic views of the phenomena under study (15).

In qualitative research, the researcher is mainly concerned with the richness of the data and reaching saturation, i.e. identifying all themes. The number of individuals needed is an important decision that a researcher has to make, depending on the goals and the purpose of the study (16). For this research study, I made the decision to interview all residents and staff members of the four community care units for people with SMI that Klimaka operates in the greater Attica area. As a result, this was a *full* sample.

In total, I conducted 50 interviews with 30 residents and 20 staff members of the four community care units. Also, I additionally conducted 5 more interviews with the legal advisor of Klimaka, two mental health policy makers from the Ministry of Health, a psychologist from Dromokaition Mental Health Hospital, and a psychiatrist from Dromokaition Mental Health Hospital, in order to gain a broader perspective on mental health policy and the problems that the deistitutionalisation policy is facing in Greece. In total, I conducted 55 interviews. The sample size is large for a qualitative research, however I decided it was necessary, in order to gain a broad perspective on all major issues relating to deinstitutionalisation in Greece.

It should also be explained that the basis for comparing staff and resident perspectives, particularly in relation to experiences in the psychiatric institutions, was the fact that several CCUs staff members used to work in institutions the same period that many of the residents were hospitalised at the same institutions, or have seen and regularly visited the residents in the hospitals during the period they were preparing them for the transition to the CCU. So in some cases, when expressing their views about care in mental health institutions, staff referred to some of the residents in this sample, who used to be patients in institutions the same period they were working there.

Many residents have been institutionalised at Dromokaition Mental Health Hospital and/or Dafni, which are the two major mental health institutions in Attica, and these are also the hospitals that several staff members used to work. For methodological consistency, in cases where this applied and had been expressed by staff members, it was explained through additional comments. However, it should also be mentioned that some of the staff members did not have previous working experience in the same mental health institutions that most residents had been hospitalised, and this may explain disparities in reporting between residents and staff.

All participants were given an information form, and had the opportunity to read it seven days prior to conducting the interview. From all residents of the four community care units, only four refused to participate, two from the hostel and two from the boarding house. All staff members on the other hand agreed to participate in the study. All participants signed consent forms.

## The use of semi-structured interviews and thematic analysis

For this particular research, semi-structured interviews were selected as the best method for interviewing participants. Semi-structured interviews present many advantages. The first one is that they are typically based on a flexible topic guide that provides a loose structure of open-ended questions, in order to explore experiences and attitudes (15). These open-ended questions, on the one hand define the area to be explored, but on the other give the researcher and the interviewee the chance to diverge in order to explore a particular response or idea in more detail (17). As a result, in semi-structured interviews, the researcher has a set of themes to cover, but the nature of this type of interview allows for conversation and redirection if necessary (17).

With a semi-structured interview a researcher can ask probing questions in order to: i) encourage participants to elaborate on the details, ii) achieve clarity, and iii) stay close to the lived experience (16). Because of their nature, and in order to ensure that really detailed information is gathered, this type of interview requires experienced researchers, with the necessary ability and sensitivity to establish rapport with respondents, to use flexibly topic guides, and to follow up questions and responses (15). With the great experience that I had from my previous research (5), and with all the issues mentioned above taken into very serious consideration, in this research I presented myself to residents as a listener, and I asked them to give accounts of their lived experience (16). The development of the themes that were covered in the interviews was informed by extensive literature review, by my previous research and by the theoretical background of the research.

For the analysis of the data, I decided to use thematic analysis, which is a widely used qualitative analytic method for identifying, analysing and reporting patterns [themes] within data (18). Basically, it focuses on identifiable themes and patterns of living and/or behavior (19). Not only does it organise and describe a data set in detail, but it goes further than this, and interprets various aspects of the research topic (18). Thematic analysis presents many advantages: 1) it is flexible, and a relatively easy and quick method to learn and do; 2) it possesses theoretical freedom and is compatible with different epistemological paradigms; 3) results from thematic analysis are generally accessible to an educated general public; 4) it can usefully summarise key features of a large body of data, but at the same time it can offer a "thick description" of the data set; 5) it can highlight similarities and differences across the data set, and generate unanticipated insights; 6) it can be extremely useful for producing qualitative analyses suited to informing policy development (18).

It is also important to note that thematic analysis can be inductive or theoretical, meaning that themes identified can be strongly linked to the data [inductive] or they can be driven by the researcher's theoretical or analytic interest in the

area of research [theoretical] (18). For my research, I used an inductive approach, and this means that analytical categories and explanations were generated gradually from the data (15). As a result, I used a process of coding the data without trying to fit it into a pre-existing coding frame or my analytic preconceptions [although I cannot deny being informed by my previous experience, and I certainly cannot claim that data were coded in a "vacuum" in terms of epistemology (18)].

The next step was to examine the codes for patterns-themes, and then reintegrate and organise the data around central themes and relationships drawn across all the cases and narratives (16). This meant that I had to sort the different codes into potential themes, and then collated all the relevant coded data extracts within the identified themes. It is important to keep in mind that some initial codes ended up forming main themes, whereas others ended up forming sub-themes, and others still had to be discarded (18). The goal was that data within a theme would cohere together meaningfully, while keeping a clear and identifiable distinction between themes. As a result, all the collated extracts of each theme needed to form a coherent pattern.

My main goal was that the final report would provide a concise, coherent, logical, non-repetitive and interesting account of the story the data told. The aim was to provide "thick description" to the readers, meaning integration of descriptive and interpretive commentary when presenting findings (20). In order to do so, I made sure that my analytic narrative went beyond description, and made an argument in relation to my research questions.

#### **Results-Discussion**

## A. Mental health institutions offering temporary asylum

As explained in the Introduction, the notion of "asylum" entails one's sense of feeling **safe** and **protected**. Can public mental health institutions though in Greece offer this sense of safety and security? Judging by the problems that some institutions face in Greece, with old and neglected buildings, skeleton staff and difficult living conditions, and based on the descriptions of CCUs staff members about life in mental health hospitals, it would only be natural to assume that residents in this research sample did not easily find asylum in mental health hospitals during their years of hospitalisation.

That which is impressive is that when the question was raised with the participants themselves, there were only six residents who responded that they did not feel safe and protected during the course of their therapy. Those who responded in this manner were mostly afraid of other patients in the same ward and were overwhelmed with anxiety that they may be attacked. Their fear had to do with the fact they their physical wellbeing was being threatened and also with the possibility that someone in the ward would steal their personal belongings.

Interestingly, the majority of residents felt that they did find an "asylum" in the institution. There appears to be a great

difference between residents' accounts and staff members' comments and this could be due to the following reasons:

1) selective memory from residents, partly due to the retrospective nature of their description of the period they were in institutions, which tends to neutralise negative experiences (21); 2) residents giving accounts in such a way as to portray themselves as "good patients" through avoiding criticism of the mental health institutions services and staff; 3) overemphasising of negative features of mental health institutions by CCUs' staff, in order to stress the difference between the two settings; 4) overemphasising by CCUs' staff members of the brutality of the institutions in order to portray themselves as compassionate and caring and the residents as vulnerable people in need of their care and support.

However, the striking difference in perception supports that the notion of Thirdspace – the lived experience of residents – can be very different from the perception of either visitors or staff members. It appears that the physical fabric of the institution – the Firstspace – is of far less importance for residents than the notion of Thirdspace, meaning their own lived experience.

As a result, the majority of residents in this research sample felt rather safe and protected while in mental health hospitals, and believed that institutions provided to them a "temporary asylum". Still, however safe and protected they felt, they never felt that the mental health hospital had become their actual home.

The notion of temporary asylum that residents experienced in mental health institutions mainly revolved around five axes:

1) Financial security; 2) Stress-free daily routine; 3) Segregation from the pressures of the outside world; 4) Good or neutral relationship with staff; 5) Trust in treatment.

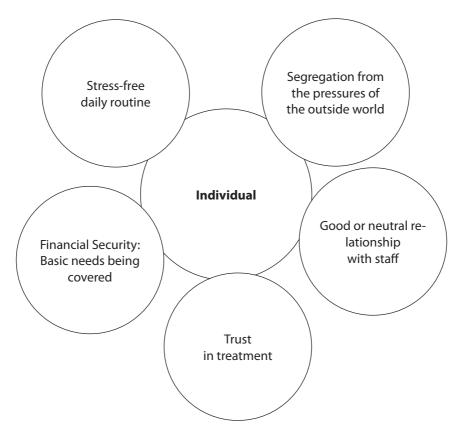


Figure 1. Notion of temporary asylum provided by institutions

#### 1) Financial security:

The notion of "asylum" appears to be that of a place offering shelter and protection, covering all basic needs of residents while in mental health institutions, including food, housing, heat and clothes.

In the majority of cases, the residents had neither a pension nor any kind of benefit when they were committed to the psychiatric hospital. The positive thing however - as far as their finances are concerned - was that when they were committed to the psychiatric hospital the social services were mobilised so that they would receive a pension. For the majority of residents, while the procedure for the issue of a pension or a welfare benefit had already been initiated, a long time passed before they could receive the money. In most cases they would receive it long after they had been transferred to community care units. Therefore, during their hospitalisation in the psychiatric hospital, what would usually happen was that their expenses would be covered by the family. In many cases, this money would be enough to cover the residents' needs inside the psychiatric hospital.

Within the sample of residents that took part in this research there were however some residents who felt that the money brought by their parents (or their pension) in the hospital was inadequate. This could be attributed to 3 reasons: a) the dire financial situation that the family of the resident might have been in, b) the lack of management skills of the resident and c) thefts that have been reported to have taken place within the psychiatric hospital. However, with all their basic needs being covered, most residents while in mental health hospitals

felt that did not have the same pressuring financial problems that they experienced in the outside world.

#### 2) Stress-free daily routine:

In this research study, a large group of residents mainly enjoyed the leisure activities and social character of the hospital. These residents described a rather monotonous repetitious everyday schedule, with little participation in any occupational therapy programmes. What they seemed to enjoy the most was the social character of the hospital. Most of all, it was the daily activity of going to the hospital's coffee shop, that residents did not want to miss, not even for a single day.

What is very interesting in this group is that most of them did not mention the hospital's everyday life schedule in a negative way, but rather as a daily routine to which they had become accustomed. Though studies on life in mental health institution often describe psychiatric hospitalisation as a negative, demoralising and in some cases dehumanising experience (22, 23), as the residents from this group have demonstrated, there are also some positive aspects of life in the hospital. A very interesting point is that most residents in this group actually *enjoyed* and *liked* this relaxing everyday life, with not so many stimuli, constituting a stress-free daily routine that did not put any pressure on to them. For these residents the hospital provided a place where they found reasonable comfort and an undemanding life with dignity.

For a second group of residents, participation in occupational therapy was something that they did enjoy, however they wanted to do this from time to time, without undertaking commitments on a daily basis or the obligations of a more stable form of work.

### 3) Segregation from the pressures of the outside world

From staff members' and residents' descriptions it seems that residents were used to the specific environment that mental health institutions offered. Despite the fact that most hospitals' buildings were rather old, they were built in very large green areas with a number of places within the hospitals' grounds that residents could visit. Mental health institutions offer outdoor spaces and areas to walk in quiet, green environments, and these may act in many cases as therapeutic landscapes (24). This secluded and peaceful environment appeared to have a dimension of therapeutic landscape to residents. As a result, a novel dimension for the term "asylum" is that of segregation from the pressures of the outside world in a peaceful environment, which offered the opportunity to residents [while in mental health institutions] to follow their own schedule, without being bothered or pressured to work or to participate in any activities they did not wish to.

#### 4) Good or neutral relationship with staff:

Several residents and especially those who have been recently institutionalised usually mentioned that they had good or neutral relationships with the psychiatric clinic's staff without much elaboration. In some cases, the residents reported that they perceived the relationship with staff as very good and this had helped them to realize the need to stay in the psychiatric hospital and the need for treatment. These kinds of relationships were not rare, but at the same time they were not easy to develop within the asylum environment of the psychiatric hospital. When and if these developed, however, it was a factor that helped the residents.

All this of course does not mean that things were always smooth and easy between residents and staff members of institutions. In a few cases, residents mentioned that they were constrained in certain occasions, because of their aggressive behaviour. This could be attributed to the lack of staff, training, institutionalisation of staff, burn out, and controlling relationships that are developed within the asylum between staff and patients.

What is striking though again, is the difference between residents' accounts and CCUs' staff members' perception: according to staff members of Klimaka, some residents in hospital were so neglected and so deprived of any human contact that they were completely withdrawn and silent. According to Klimaka's staff members, the indifference of hospital's staff both towards the residents' reactions and the proper administration of their medicine also had an impact on the course of their treatment.

It is very important to emphasise that these derogatory comments about mental health hospitals were only made by Klimaka's staff members and not by residents themselves. This once again shows the great difference between the notion of Firstspace – the physical dimension of a place, Secondspace,

i.e. the relationships developed in a space, with the notion of Thirdspace, which is the lived experience of residents.

#### *5) Trust in treatment:*

About two thirds of the thirty residents who participated in this study, did not know what kind of pharmaceutical treatment they were receiving while in mental health institutions, although in most cases they believed that the pharmaceutical treatment was helpful for them and they had faith in the prescribing process by the hospital's psychiatrist. Although some of them did not know the names of the drugs they were receiving while in hospital or the active substance they contained, at the same time they recognised the drugs of their everyday treatment from the morphology of the pills they were getting.

It seems from residents' comments that although they had faith in the prescription of the doctor, at the same time they themselves did not have any particular say in the configuration and shaping of the pharmaceutical treatment that was ordered for them.

About one third of the residents who participated in this study were *fully aware* of the drugs they were receiving while in hospital. What is impressive is that again most did not know *why* they were receiving those drugs as far as SMI is concerned, and they could not influence the changes that were happening to their treatment or the prescription process in any way. Still though, they had faith in the prescribing process.

Lastly, it should be mentioned that only a small number of residents ever received psychotherapy while in mental health institutions, but for those who did it was beneficial to them.

## B. Community Care Units offering temporary and permanent asylum

The majority of residents of all four units of Klimaka felt safe and protected, and seemed to have found "asylum" in the CCUs, with all the basic parameters of their life being improved. A very interesting parameter that appears to be different in relation to the residents' previous life in mental health institutions is that a fairly big percentage of the residents – nineteen of thirty residents – felt at home in the CCUs. Two subcategories can be found within this population: 12 residents felt that the CCU was their permanent residence, while for 7 of them it was their temporary one, a transitional stage before moving on to more autonomous living conditions. Some however still believed that their former house was still their home. As a result, CCUs appear to offer an "asylum" more permanent in nature than mental health institutions did.

What is again impressive though is the difference between the notion of Firstspace and Thirdspace: one would assume that since residents got transferred to community care units with considerably better living conditions than mental health institutions, the transition would automatically be easy and smooth. The lived experience however of residents shows that the transition had some difficulties for them. What many residents of Klimaka's CCUs found difficult at first, was to adjust to an organised daily programme which had certain rules, and this relates not only to taking care of their personal hygiene, but also helping with the daily chores, and living a daily life with considerably more stimuli than in mental health institutions. After an initial period of adjustment however, residents got used to their new daily programme and became more active.

This helped the residents to start taking care of themselves with the aim of becoming as autonomous and self-sufficient as possible. This could potentially help them, especially the younger residents to eventually move on to totally autonomous living conditions.

There appears to be a contradiction between the notion of Firstspace and Thirdspace for two more reasons as well: one would expect that because of the smaller scale of units, and the higher degree of freedom and contact with the neighbourhood, residents would easily find asylum in the CCUs. The lived experience of residents though indicates that this was hindered in some cases by the lack of safety residents felt

in certain dangerous neighbourhoods, along with the stigma from the local communities. CCUs in smaller areas such as the island of Aigina, initially faced serious problems.

The situation was not easy for residents of CCUs in urban neighbourhoods either: although big cities offered a "blessed anonymity", at the same time there had been incidents indicating that that the stigma associated with mental illness is still prevalent. Progress though has been made in all cases, indicating that for future residents of CCUs the process of finding asylum in the community could be easier and smoother.

Besides these difficulties, in most cases residents of all four units of Klimaka managed to find asylum in the community, and this notion of asylum revolved around seven axes: 1) Financial security; 2) Enriched daily routine; 3) Friendships and wider social networks; 4) Increased degree of freedom and contact with the neighbourhood; 5) Good relationship with staff; 6) Trust in treatment and increased awareness; 7) Absence of abuse.

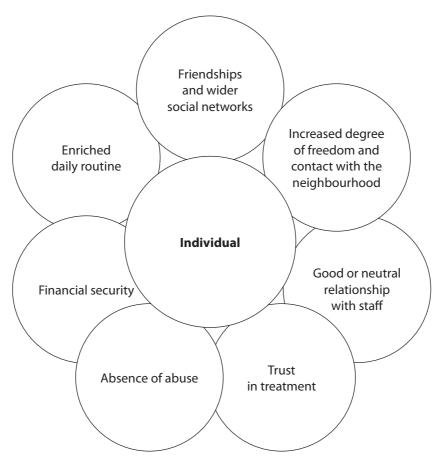


Figure 2. Notion of temporary and permanent asylum provided by CCUs

#### 1) Financial security:

One reason why residents felt safe and protected is that they found themselves in a small scale place where all their basic needs – food, water, heating and treatment - were covered. Also, because of the better living conditions that the CCUs offered comparing to the impersonal mental health institutions, the residents felt that their quality of life greatly improved.

A very pleasant fact which shows that there had been considerable improvement during the period of time when

residents were transferred to the community care units is that they were able to receive their pension from the Greek Social Security Organisations or other benefits from the Social Welfare. Two residents had an extra income apart from their money they received from the State, through some form of work.

Since all the basic needs were covered by Klimaka, the money residents had went for their personal basic expenses such as buying cigarettes, going out, buying coffee and some personal hygiene things and clothes. Most residents thought

this money was enough, in some others of course just enough to cover these needs. Most residents needed during their first months after being transferred, serious help and training in order to learn how to manage their monthly income. The staff, along with the residents, organised a weekly expense planner, which assessed each resident's needs individually. What is impressive is that some residents could not only manage their money well, but they could also help their fellow residents to manage their own money better.

Few residents reported financial concerns about the serious economic crisis that Greece is experiencing, which has resulted in cuts in pensions. This however was an issue mainly reported by staff members of the CCUs, who described the concerns that residents expressed to them, both at a microeconomic and a macroeconomic level.

#### 2) Enriched daily routine:

For most residents in all four CCUs of Klimaka, the parameters of daily occupation, participation in occupational therapy and in creative group activities demonstrated significant improvement in relation to the psychiatric hospital. Some residents even went a step further, and developed skills and interests they never had had the chance to develop in the psychiatric hospital. What is even more encouraging is that a small number had a regular job and seemed to enjoy the benefits of this, i.e. the fact that they got paid, came into contact with many people and spent their time in a creative way. Last, but not least, all residents seemed to enjoy the leisure activities offered by Klimaka's CCUs, although some wished for more organised outings and excursions and on a more frequent basis.

#### 3) Friendships and wider social networks:

The number of friendships and social networks that residents managed to establish while in the community care units seemed considerably increased and more developed in relation to what existed while these residents were in the psychiatric hospitals. The development of close friendships appeared to be age and functionality related. Most residents developed friendly relationships and those who did not, could still enjoy the company of the rest of the residents and shared activities. Residents also learned to function as members of a team and they seemed to care for one other.

## *4) Increased degree of freedom and contact with the neighbourhood:*

The degree of freedom that the residents experienced while in the community care units in relation to the time they had lived in the psychiatric hospital was greater and improved. As was previously highlighted, there was no possibility within the psychiatric hospital to be able to go out, so the contact with the neighborhood had been nonexistent. It appears that the residents of the community care units had more freedom than in the psychiatric hospital, for example to go to the Occupational Therapy Centre which was located close to the units, or go out for a coffee or a walk, along with staff members or friends from the unit. This parameter however was restricted to

a certain degree, based on certain conditions: the functionality of the resident, his or her mobility, and the seriousness of the SMI symptoms, along with the safety of the area around the community care unit. Contact with the neighbourhood was also difficult in some cases because of the stigma residents experienced at first, however it seems that the situation became easier as time passed by.

#### *5)* Good relationship with staff:

Another reason that made residents feel that they have found "shelter" in the CCUs was the good relationship that most of them developed with staff members. A critical factor that promoted this was the high staff/resident ratio in the CCUs. Consequently, there was a lot of intensified care and attention, things that they did not have in the psychiatric hospital and they would usually not get if they were at home. The residents had the chance to express any of their needs and they knew that their voice would be heard. The 24 hour presence of the staff who worked in shifts, also created a sense of a steady presence since residents knew that even if something happened in the difficult night hours, someone was there for them. One cannot exclude the possibility that the residents might have tried to give accounts that would portray themselves as "good residents" through avoiding criticism of the CCUs' services and staff. Still though, the overall impression indicated improved relationships between residents and staff members, in comparison to those developed in mental health institutions. However, at the beginning, there were some frictions between staff and residents, and this was mainly from the difficulty residents experienced at first to get used to a daily routine with certain rules. After this initial transitional period, things became smoother, and most of them managed to develop close relationship with staff.

The issue of pharmaceutical treatment and psychotherapy appeared to have several differences – but also improvements – in relation to what the residents had received in the psychiatric hospital. Almost all residents of the units believed that the pharmaceutical treatment was helping them. Moreover, more residents knew the kind of pharmaceutical treatment they were receiving and in fact this number increased as we moved on to more independent living conditions. This comprehension and realisation along with the insight about the pharmaceutical treatment was very important in order for some residents to experience enhanced autonomy. This in turn facilitated some residents to make a successful transition to more independent living conditions either in the protected flat or living alone outside the unit.

Another positive feature of Klimaka's way of operation was the significant monitoring of the residents from the staff [both doctors and nurses] and the cooperation between the staff and the residents. This close monitoring facilitated immediate treatment of possible relapses, which could happen to residents.

Finally, another parameter that helped the residents greatly and was an integral part in their treatment was psychotherapy. The type of psychotherapeutic approach in the CCUs of Klimaka had a counseling nature and aimed to help residents

mainly with daily issues instead of long-term ones. In the CCUs, the framework was such that residents knew that they could visit a psychologist at any given moment and discuss anything that bothered them, when they needed it, without feeling that they were obliged to do so.

#### 7) Absence of abuse:

The majority of residents of all four units of Klimaka felt safe and protected. This came in contrast with the environment of mental health institutions, where in some cases residents mentioned about incidents of abuse by staff and fear for some other patients in the same ward, who either tried to harm them or to steal their belongings. This parameter seemed to be greatly improved in the CCUs.

**In conclusion**, based on the lived experience of CCUs' residents in this study, one understands that the notion of "asylum" does not necessarily represent a physical entity (i.e. the building), but in fact a set of social, economic and affective parameters. Findings suggest that "asylum" is not a place, but mostly a set of interrelated criteria which if met or addressed by the mental health care services, "asylum" can possibly be achieved for people with SMI anywhere.

## C. Recommendations for the practice of deinstitutionalisation in Greece: Non-contributory and contributory factors to a successful deinstitutionalization

Based on the notion of Thirdspace – i.e. the lived experience- of residents in this study, there appeared to be certain non-contributory and contributory factors to a successful deinstitutionalisation. On the non-contributory side, one factor that created difficulties for some residents when they first got transferred to the community was the fact that they had to get used to an everyday schedule with rules and to a new way of life which involved participation in everyday activities or chores. Secondly, in a few cases, residents found themselves having to share accommodation with people they had little in common with and hence found it difficult to get along with. Thirdly, in some areas, regardless if it was an urban neighbourhood or a small rural area, residents of CCUs found themselves having to deal with the heavy stigma that is associated with SMI in Greece.

On the contributory side certain factors greatly facilitated a successful deinstitutionalisation: A first factor was the change in environment, which the great majority of residents from this research study seemed to enjoy. In this new environment, the pattern of their daily life changed sharply, and they began to participate in daily chores, organised occupational therapy programmes, trips and excursions; they also seemed to have a greater degree of freedom and contact with the neighbourhood, creating at the same time a new social network. A second factor was the high staff/residents ratio in the CCUs, which enabled staff to spend more time encouraging residents to participate in various activities, helping each one of them substantially. Thirdly, the greater awareness residents

had about their drug treatment, along with their participation in psychotherapy, greatly helped residents to better adjust to their new life in the community.

## D. Recommendations for future mental health policy implementation in Greece

Based on the lived experience of residents in this study, there are several important lessons for future mental health policy implementation:

a) There is great need for reinforcement of law for involuntary commitment of patients with SMI to public mental health hospitals:

All residents that participated in this study were involuntarily admitted to mental health institutions. What is striking is that most residents in this study did not mention at all their involuntary commitment to a mental health institution, and for the residents that did describe the scene, it was an extremely traumatic event. The law explicitly describes the way that involuntary commitment should be carried out by authorities, with the examination of a patient by two psychiatrists and then accompanied to the mental health hospital or mental health unit by specialised psychiatric staff (25).

In practice, however, it has been found that serious violations have been occurred for the last 30 years. While police interventions should only occur under extreme cases, in reality these interventions have become common practice. Actually due to this type of intervention, side effects have been noted such as: patients are transferred in cuffs/chains as if they were perpetrators, patients are kept in prison for days devoid of their necessary treatment/medication and police interventions take place in events that no intervention is needed. The Hellenic Psychiatric Association has suggested that EKAB (Emergency Aid Centre) do these types of involuntary admissions. More specifically this should be done either by qualified psychiatric nursing staff or by the Health Centres and their ambulances (26). If those services had provided the necessary organisation, then the police intervention would be restricted only in the event of violent acts or destruction inflicted by a patient. As a result, there appears to be a need for serious reinforcement of law, instead of relying on police for involuntary commitment.

b) Health services need to safeguard the existence of some form of mental health hospital for those who need it:

From the lived experience of participants in this study, it appears that residents managed to find a temporary asylum while in mental health institutions. A basic element of the notion of "asylum" that mental health hospitals offered and community care units did not, was the element of segregation from the pressures of the outside world. This greatly helped residents in times of crisis to live an everyday life with practically no pressures, but with dignity as well. The segregation from stressful stimuli helped them to calm down and to gradually regain their strength in order to face life in a community care unit. As a result, mental health services should safeguard the existence of some form of mental health hospital or psy-

chiatric wing in general hospitals which can offer to patients with SMI in periods of crisis the element of segregation from the pressures of the outside world.

c) Families of patients with SMI and of residents of CCUs need additional support and assistance by the state:

From the lived experience of participants in this study it appeared that in some cases residents experienced financial exploitation by their family members and/or had tense relationships with them, feeling angry that their relatives had ordered their involuntary commitment to hospital. One reason behind the problems that families faced has to do with the heavy stigma that is associated with mental illness in Greece.

All this shows that families caring for individuals with SMI in the Greek context, either patients in mental health institutions or residents of CCUs, need additional support and aid from the State. Family members experience a lack of assistance and support and as a result, they may feel unable to cope, resulting in great difficulty in any attempt for communication with their ill relative. Although the PanHellenic Family Association for Mental Health (SOPSY) organises support programmes such as counseling groups and support sessions for family members (27), this was not available up until the late 1990s. Even nowadays - particularly during the financial crisis that Greece is experiencing - such efforts need to be reinforced by the State. More importantly, there is a great need for educational programmes for families of individuals with SMI hospital patients or residents of CCUs - in order to learn the symptoms, treatment and options that both they and their relative with SMI have.

d) There is a great need for training programmes for SMI for the general public in Greece:

From the lived experience of residents in this study it appeared that SMI is heavily associated with stigma in Greece, even nowadays. Finding asylum in the community has not been an easy process for residents, especially during the initial phase of operation of certain CCUs, particularly in smaller rural areas. The situation has not been easy for residents of CCUs in urban neighbourhoods either: although big cities offer a "blessed anonymity", at the same time there have been incidents indicating that the stigma associated with mental illness is still prevalent. As time passes by though, communities seem to get accustomed. However, an intensified educational programme for the general public concerning mental illness and how to treat people with SMI in general, and residents of CCUs in particular, living in our neighbourhood, could greatly help the change of scenery in Greece. Special seminars should get organised for high school students as well, in order to educate people at a much younger age.

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