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Patients' Experiences of Deinstitutionalization from Long-Term Psychiatric Care in Athens, Greece: Shifting Notions of "Asylum"

Dorothea Lentis

Biomedical Sciences Program, Department of Science and Mathematics, The American College of Greece

Abstract

This research study examined the experience of deinstitutionalization amongst a group of 24 long-term residents of a psychiatric hospital in Athens, Greece. Participants varied in age and gender, but all suffered from schizophrenia. The main issue this study explored was what was the notion of "asylum" for these patients. For them, "asylum" revolved around five basic axes 1) having friends and social network, creating a sense of acceptance, 2) trust in stuff and treatment, 3) financial security, 4) absence of abuse, 5) stress-free daily routine. From the patients' interviews, four different interpretations of "asylum" as a typology were developed: for one group the mental hospital was perceived as offering "permanent asylum", and was even perceived as a "home"; for a second group, the mental hospital offered "temporary asylum", since their familial home could no longer offer them "asylum", until their next transfer to a Community Care Units (CCU); for a third group, the mental hospital offered "temporary asylum" during periods of serious relapses that patients experienced while in CCUs; for a fourth group of patients, the CCUs offered "permanent asylum", indicating a successful transition to a community.

Keywords

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

Corresponding author: Dorothea Lentis, Biologist BSc, MPhil, PhD, Specialized Health Researcher, Assistant Professor, Biomedical Sciences Program, Department of Science and Mathematics, The American College of Greece, e-mail: DLentis@acg.edu

Introduction

Since the onset of the community mental health care movement, mental health professionals in Europe and in the U.S.A have come to view the process of deinstitutionalization of patients suffering Severe Mental Illness [SMI] as a crucial step towards life in community. The process of deinstitutionalization is a reality that Greece also has been facing since the early 2000s, according to the general policy of deinstitutionalization practiced in all countries of the European Union. As a result, the closure of many psychiatric units leads to a population of chronic patients suffering SMI, who have to leave the hospital and survive in the community, with an after-care follow up in community care units.

This particular research (1) took place in "Dromokaition" Mental Health Hospital in Athens, which is a state hospital, located in the southwest of Athens. A group of 24 chronic patients suffering from schizophrenia, that were stable for over a period of one year were interviewed with semi- structured interviews, prior to their deinstitutionalisation. Schizophrenia was diagnosed by the state hospital's psychiatrists, according to the diagnostic criteria of DSM IV (2, 3). The originality of this research is that for the first time in the Greek context, patients had the chance to express their own feelings, hopes and expectations as far as deinstitutionalisation is concerned. The same individuals were interviewed again, six months after they had been transferred either to community care units or to their familial home, in order to explore the reality of life in the community.

Internationally, there has been a growing requirement in the past two decades for more patient-centered research, exploring patients' perceptions of quality of services (4, 5). 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 (6, 5).

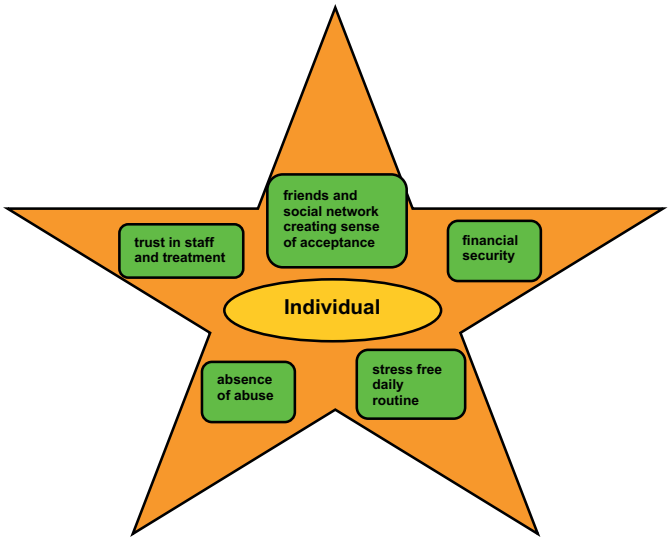
One of the main focuses of this research was the shifting meanings of "asylum". This study let patients suffering from schizophrenia to speak to the centre – the policy makers – of how they perceive the notion of "asylum", as a place offering safety and security, so that positive features of the asylum can be recreated in the community and negative ones be avoided. The value of hearing the stories of people living with long-term mental illness was to obtain an inside perspective of what constitutes "asylum" for them. Lastly, from this study, some very interesting conclusions emerged, of what makes for an unsuccessful transition to community care, and what makes for a successful one.

Parameters of the notion of "asylum"

One of the main issues this study explored was the patients' perception of the notion of "asylum". Participants in this study, as recipients of the services provided by the asylum as a mental health institution, had a unique opportunity to voice their views on whether they had been able to find "asylum" as a place offering protection and security, within the asylum. Thus, each and every patient was able to express his or her own view on what the parameters establishing a place as "asylum" are.

The notion of "asylum" refers to a place offering safety, security, protection, refuge from attack, and a sense of comfort (5). In other words, "asylum" offers a shelter from danger or hardship. While expressing their views on the notion of "asylum" patients shed their own individual light on this notion: For them, the notion of "asylum" revolves around five basic axes: 1) having friends and social network creating a sense of acceptance, 2) trust in staff and treatment, 3) financial security, 4) absence of abuse, 5) stress-free daily routine. Based on these five major axes, the notion of "asylum" may be visualized as a star which, by means of its five central axes, enfolds each patient within its core, offering security and protection.

Figure 1: Parameters of the notion of "asylum"



Patient's views about the notion of "asylum" – Differential experiences of "asylum"

Drawing on patients' perceptions, four different categories of patients emerged, having four different perceptions of asylum and where "asylum" occurs:

For one group of older patients, there was a clear desire to remain in a place that is both familiar and "safe" for them, and this was the mental health institution. This group expressed favorable attitudes towards the institutional environment. For them, the hospital provided a supporting atmosphere, where they were helped by staff, able to be benefitted from treatment, and were happy with the social networks they had established in the institution. These patients also enjoyed their daily routine in the institution. These individuals considered the hospital as the most preferential environment in which to live.

These were all older patients, who became institutionalized after many years spent in the hospital. For them the hospital represented a place of safety, providing physical and emotional support. Their advanced age made them fearful of change, where the pressures of everyday life could prove too difficult

to adapt to. After their long period of institutionalization in the mental health hospital, these patients had grown accustomed to this very specific way of life so much, so as to greatly fear the prospect of having to transfer at all. The intensity of their fear was so great as to prevent them from even considering such an eventuality. The patients in this group felt that the mental health institution offered them "permanent asylum", sheltering them from the pressures of the outside world. This element of permanence made them think of the hospital not merely as a place offering the basic parameters of an "asylum" – protection from danger, safety, security – but also their "home".

Nevertheless, the notion of "home" entails some other parameters that were not included in the notion of "asylum". "Home" conjures the image of a "…safe haven, bringing out feelings akin to what the womb must have felt like – warm, secure, cared for, a sense of belonging" (7, pg. 1). As the popular adage proclaims "home is where the heart is", and clearly for these patients their heart was at the mental health institution. The patients in this group paid no heed to the decrepit and drab buildings of the public psychiatric hospital, nor did they mind the neglect of the interior decor. For these patients the physical fabric of the place in which they resided was of far less importance to them than the social fabric of the place. It is the human relationships that made the mental health institution effective not only providing "asylum" in its original sense, but also becoming their home. For these individuals it was obvious that their "home" – meaning the mental health institution – had very little to do with bricks or furniture. It had everything to do with the sense of belonging they experienced in it. To these patients, the hospital offered "permanent asylum" and, at the same time, fulfilled the basic definition of home as a place of loving, caring and belonging.

For this particular group, the transferability of the notion of "asylum" to a community care unit was a very hard task. Due to their advanced age and their lengthy institutionalization, these patients found it hard to disengage themselves from the hospital. For this reason, any attempt at deinstitutionalizing them would require a particularly well-thought-out plan and a special strategy in order to avoid failure in implementing deinstitutionalization. Given their very old age, there even was a case of leaving these patients within the institutional setting, until natural attrition took its own course for this particular group.

For a second group of patients, the mental health institution offered a more "temporary asylum" in nature. For these individuals, repeated attempts at deinstitutionalization and transfer to their parental homes had taken place. However, all attempts had been unsuccessful for a variety of reasons. In most of the cases, the parents of the patients – who were the prime caretakers – had grown old, and either passed away or were unable to care for the patient suffering Severe Mental Illness. In several of the cases, serious domestic problems and tension ensued because the patients' relatives could not endure the patients' exhibiting the symptoms of their psychological disorder or the outbursts they were prone to. In some instances, patients had been abused or exploited by their relatives in exchange for the hospitality they had extended. Lastly, in some other instances, families found the task of the constant, 24-hour patient care too demanding and were unable to cope. All these reasons illustrate that it is extremely difficult for the family to support the patient without adequate familial and state support (8, 5). Amongst this group, the family home felt short in offering them "asylum", resulting in the patients' return to the mental health hospital. For some, this process had been repeated several times, resulting in what is commonly known as the revolving-door phenomenon.

For this group, the hospital was viewed as offering them "temporary asylum" as there was an assumption on their part that their in-patient stay would be short-lived. The hospital was seen as giving them the chance to put some distance between themselves and their domestic environment, to alleviate the pressure, to feel calmer and more relaxed, with the aim of moving back into the community at some future date. In sum, the asylum made them feel secure and protected during periods of crisis or breakdown in their mental health status. One should also not neglect the fact that mental health institutions, although having old and rather neglected buildings, at the same time act as therapeutic landscapes as they offer outdoor spaces and areas to walk in quiet, green environments (9). This helps even further patients to distance themselves from the pressures of the outside world, relax and recuperate.

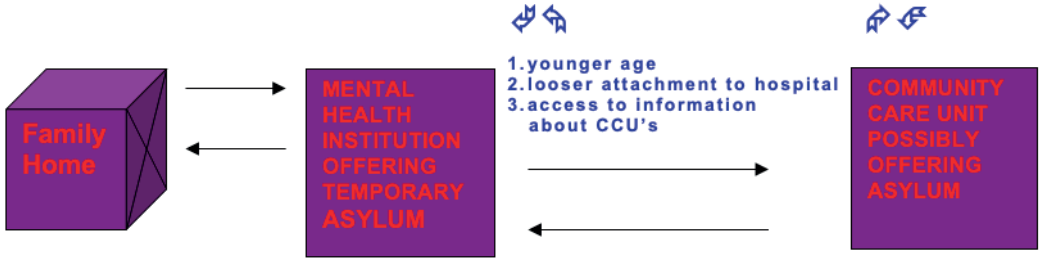
Patients laboring under the conviction that their stay at the hospital would be a short-lived one, tended to form relations within the hospital that were loose in nature. Although they did socialize with the other patients, they did not develop close friendships, so that when the time came to leave the institution they did not feel devastated by the loss of close friendships. These patients also believed that, once transferred to the CCUs, they would be able to form new friendships there. This group felt their treatment was beneficial and that they should continue it after moving to a new CCU. Their views regarding professional care and support inside the hospital, however, varied considerably from being very positive to neutral (or even negative in a few cases). Furthermore, most of the patients hoped that they would be able to participate in occupational therapy programs offered by the CCU, although that did not necessarily mean that they wished to undertake the serious commitment a permanent job entails.

Whilst patients in this group considered the possibility of getting transferred to a CCU, this was not always their first choice. Some still wished to return to their parental home although they knew it was unlikely. Critically, amongst this group, there was a clear perception that transfer to a CCU was not something that was permanent or irreversible in nature. They believed that if they were not happy with life in the community, they could always return to the hospital.

To conclude, for the patients in this particular group, the door to their parental homes – where they had hoped they would find "asylum" – had firmly shut behind them. They thought of the mental health institution as offering them "temporary asylum" and felt that their stay in hospital would not be of long duration. The patients in this group did take under advisement and considered the prospect of transferring to various CCUs. In that, they were assisted by their younger

age – late 30's - early 50's – as well as by the looseness of the relationships they had formed within the hospital: they felt that these bonds of friendship within the hospital could be easily severed and easily replaced by new ones at the CCUs. Interestingly enough, patients in this group believed that, at any given moment, they could return to the hospital if something did not go according to their expectations in the CCUs. Subsequently, when considering the prospect of their being transferred they felt that the hospital door would remain open for them even after they had gone. They also believed that a key element behind their successful transfer lied with their being better informed in advance about life in CCUs.

Figure 2: Mental institution as a place of "temporary asylum" to patients who can no longer live at their family home.



For a third group of patients there was an unsuccessful transition to community care, and they experienced serious relapses while in CCUs – although they really liked life there. This resulted in their having to return to the mental institution, where they found "temporary asylum" until their next transfer.

There were serious reasons underlying the relapses patients suffered while in CCUs: poorly managed transitions from hospitals to CCUs combined with multiple changes in treatment that were poorly explained to patients, resulted in confusion that increased the anxiety of patients, resulting in a greater likelihood of an unsuccessful transition.

The patients in this group often had to endure the ordeal of multiple transitions: being transferred to a CCU for a short period of time only to be transferred again to a second unit. These were stressful events for these patients who, having become accustomed to a certain way of everyday life were essentially required through this process to change their daily routine all over again. Another factor that brought stress into their lives was their transfer to CCUs with which they were not familiar nor had they had an opportunity to learn anything about. As a result, the patients had a hard time adjusting to their new surroundings.

Yet, patients experienced difficulties even when they had already been transferred to their CCUs. It was very taxing for them to adjust to this new way of life in the unit where, in all likelihood, the type of everyday life being promoted involved more stimuli and required patient participation in various unit activities or chores. What is more, it cannot always be taken for granted that a patient will be able to get along with all the other residents of the community care unit.

Nevertheless, patients often had to deal with the even greater difficulty of having to endure frequent changes in their drug treatment. Every time the patients were transferred to a different unit, their drugs changed. What was more, the doctors did not always have the opportunity while these changes were taking place to explain to patients the reasons behind the change. Thus, the patients' perception of their treatment was that they felt disempowered from the prescription process. This perception when coupled with the facts that for some people with schizophrenia, drugs are not always effective, and that people suffering schizophrenia are more likely to experience relapses than people suffering from other forms of severe mental illness (10, 11), show how crucial all these factors are. Additionally, a crucial factor behind the relapses of many of the patients caught in the "revolving – door" phenomenon, was their non-compliance with the prescribed medication.

All the difficulties and factors previously mentioned may had acted as triggers setting off relapses in the patients, who were then forced to transfer from the CCUs back to hospital. For the patients in this group, the asylum was not viewed as their "home" but rather as a place offering "temporary asylum" until their next transfer. They felt that the mental health institution helped them in distancing themselves from the stress-producing factors they may had dealt with, while still residing in the CCU. They also felt that the hospital did not exert on them any particular pressure to participate in any of the hospital activities and thus were given the opportunity to relax within a routine that offered a more leisurely pace, as well as fewer stimuli leading to stress.

In spite of the difficulties and factors that may had triggered relapses in the patients in this group forcing them to return to hospital, a new prospect started appearing for them on the horizon: The possibility that certain community care units could offer them "asylum", and even, ultimately, become their "home". It was also evident that among the various types of CCUs, much smaller environments based on shared living in a protected apartment, for example, was more symbolic to patients as "home".

In that type of smaller environment, where life is shared with fewer housemates and where the patients were given the chance for more independence and initiative, the patients gradually began to feel that they were taking steps towards a more independent life within the community. In that, they were aided by the smaller environment which offered them not only the basic parameters of an "asylum" – protection, acceptance and adequate coverage of their basic needs – but it also became "home" creating a sense of belonging.

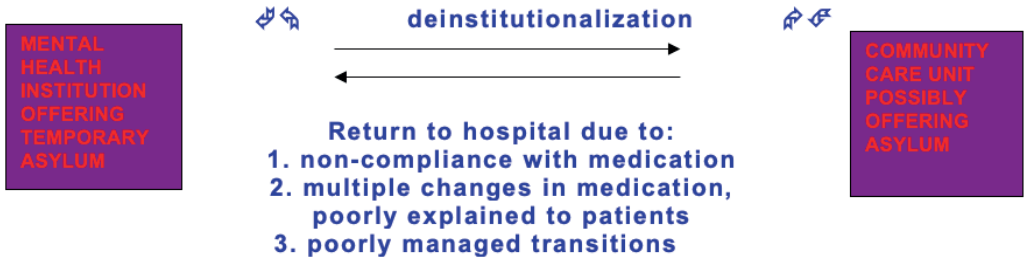
Lastly, we need to mention that there is hope for better pharmacological treatments in the future: in 2024, a new an-

tipsychotic drug received approval by FDA, that combines two medicines: xanomeline and trospium chloride. This drug, activating specific muscarinic receptors in the brain that may be related to the symptoms of schizophrenia, is expected to be a game changer, as it has fewer side effects, and may help patients in the future to better control the symptoms of the disease (12). This can aid towards the direction of controlling the symptoms of the schizophrenia and managing transitions more easily.

well as psychotherapy sessions. In effect, for some of the patients the drug treatment had to be reinforced during the early stage after their transfer, until they overcame their initial adjustment issues, and then returned to the usual therapeutic scheme.

Thus, by virtue of the help they received, the patients were able to make a successful transition from their life in the mental health institution to their new life in the CCUs. All patients in this group, although initially happy with their life in hospital,

Figure 3: Mental health institution as a place of "temporary asylum" to patients that experienced serious relapses while at CCUs.



For a fourth group of patients, there was successful deinstitutionalization and transition to community settings. This group represents those who had adjusted well to their new life in the community and continued to remain in their respective unit.

Initially these patients refused to be moved to any type of CCU: life in the community represented the unknown to them. They had all expressed serious concerns about all the basic parameters of life as it would be once they were transferred. The first basic parameter that gave them cause for concern was whether they would be able to keep in touch with the friends they had made within the hospital and whether they would be given a chance to make new friends in the CCU they would be transferred to. They were also concerned as to whether they would be able to get along with the CCU's staff in the same manner that they had done so with the hospital staff. A third parameter involved their finances and whether the monthly sum of money at their disposal would suffice for the basic necessities in the CCUs. Last, the patients had no clear idea about **how** their day would be spent in case they got transferred to a CCU.

Before their transfer, some of the patients had expressed the wish to keep in touch with the hospital staff and even certain hospital programs, even after they had been moved to their respective CCUs. For instance, before their transfer, some patients expressed the desire to maintain contact with the hospital's occupational therapy center, although they did not use to attend these programs. It was evident, that the only reason behind this wish was the patients' desire to leave the door open in case they ever wished to return to the mental health institution. In conclusion, these people were looking for ways to retain a link with the hospital – a "safety net" – because of their fear of finding themselves isolated in the community.

All doubts and concerns though as expressed by the patients at hospital, were soon forgotten immediately following their transfer. Their fears proved groundless, something that enabled them to break their ties with the hospital. What truly helped in dispelling the patients' fears was an intense effort on the part of the hospital as well as on the part of the CCUs' representatives, who visited the patients at hospital, to inform them on matters salient to life in the community. Gradually, the patients acquired a clearer idea of how CCUs function, as well as of the new vistas offered by life in these smaller scale units in the community.

After their transfer, patients began to shed the symptoms of institutionalization that they had developed after many years of being hospitalized, becoming more receptive to new stimuli, once they found themselves in different surroundings. The pattern of their daily routine shifted sharply when they were moved to their respective CCUs, where they began participating in organized occupational therapy programs, daily house chores, in excursions, walks and organized trips, and creating at the same time a new social network.

One factor that greatly contributed to this change was the change in environment. Some of the patients expressed a view that they felt much better in the new environment offered by their new surroundings in the CCUs, an environment that beckoned with its newly built facilities equipped with brand new furniture and offering rooms in mint condition.

A second factor that helped in this direction was the excellent relations the patients forged with the staff at their CCUs as well as the support and encouragement they received by that staff. In CCUs, there is a lower ratio of patient/staff enabling staff to spend more time encouraging patients to participate and helping each one of them more substantially.

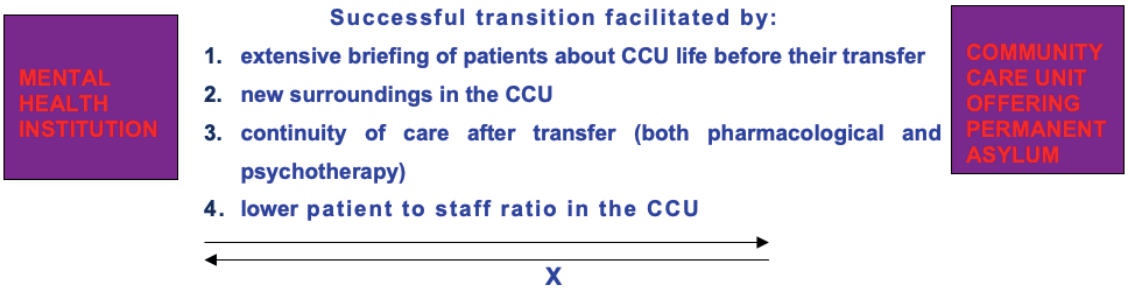
A third contributory factor had to do with the fact that the patients' treatment was never interrupted and there was a continuity of care after their transfer: once their transfer to their respective CCUs had been completed, all patients in this group continued as scheduled with their treatment, both in terms of pharmacological treatment as

definitely seemed to prefer life at their respective CCUs after their transfer there. This becomes remarkable if one takes into consideration the fact that two of the patients in this group had to be moved twice from one unit to another due to financial problems the units were having. Despite the fact that the period of almost a year that has elapsed since the time they had arrived at the units was too short a period of time for the patients to think of the units as "home", still they seemed to enjoy all the parameters of their new life. They did not seem to miss the mental health institution at all, nor did they make any mention of it. They seemed to enjoy their new life and felt that in the CCUs they had found the notion of "asylum" in its original sense. For the patients in this group, the dream of a successful transition from the mental health institution to the CCU became reality as they found "permanent asylum" in the community care unit environment.

Successful and Unsuccessful transition to community care

From the four "typologies" analyzed, there are some interesting conclusions of what makes for an unsuccessful transition to community care, and what for a successful one. In cases where the transition to community care is unsuccessful, usually patients suffer serious relapses and need to return to hospital. There are serious reasons underlying relapses: First of all, patients in some cases have to endure the ordeal of multiple transitions, without having adequate time to get used to their new way of life. Second, it is hard for patients to get adjusted to a new way of everyday life, that involves more stimuli and requires patient participation in activities or chores. Third, it is not always easy for a patient to get along with all the other residents of a CCU. Fourth, patients often have to deal with the

Figure 4: Successful transition to CCUs that offer "permanent asylum"



even greater difficulty of having to endure frequent changes in their drug treatment that are poorly explained to them. Last but not least, in many cases non-compliance with medication is crucial in triggering a serious relapse.

In cases where there is a successful transition to community care, there are several contributory factors to this. One such factor is extensive briefing of patients about life in CCUs before their transfer, that gives them a chance to acquire a clearer idea of how these units function, as well as of the new vistas offered by life in these smaller scale units in the community. A second contributory factor is the change in environment, that most patients truly enjoy in CCUs. In this new environment, the pattern of their daily routine is shifted sharply, and they begin to participate in organized occupational therapy programs, daily chores, excursions and trips, creating at the same time a new social network. A third contributory factor is the lower ratio of patient/staff in CCUs, that enables staff to spend more time encouraging patients to participate in various activities, helping each one of them substantially. A fourth contributory factor is continuity of care after transfer, both in terms of drug treatment and psychotherapy. In fact, in some cases the drug treatment is reinforced in the early stage after transfer, in order for a patient to overcome more easily initial adjustment issues.

Lastly, the study highlights the fact that exploring service users' views is very important in order to create services that reflect their needs and achieve balanced care in the community (13).

Conclusion

This study dealt with a group of 24 patients suffering from schizophrenia who were about to get released from a public mental health hospital. The main issue this study explored was what was the notion of "asylum" for these patients. For them, "asylum" revolved around five basic axes 1) having friends and social network, creating a sense of acceptance, 2) trust in stuff and treatment, 3) financial security, 4) absence of abuse, 5) stress-free daily routine. From the patients' interviews, four different interpretations of "asylum" as a typology were developed: for one group the mental hospital was perceived as offering "permanent asylum", and was even perceived as a "home"; for a second group, the mental hospital offered "temporary asylum", since their familial home could no longer offer them "asylum", until their next transfer to a Community Care Units (CCU); for a third group, the mental hospital offered "temporary asylum" during periods of serious relapses that patients experienced while in CCUs; for a fourth group of patients, the CCUs offered "permanent asylum", indicating a successful transition to a community.

Through the experiences of the patients in this study, important insights have been gained on how we might improve present policies on deinstitutionalization. It has become clear that individuals deinstitutionalized from state hospitals **can** successfully live in community care units, if all parameters of "asylum" are put in place. The great challenge health services in Greece are facing is to create the appropriate conditions that will help patients live a more autonomous life within the broader community.

One particular aspect of this research, that was at the same time both a strength and a weakness, was the fact that the design of the research was focused on patients' interviews. This represents the uniqueness of this research in the Greek context, but at the same time it created some limitations: For example, in some occasions during the course of this research it would had been helpful to have the staff's view or the relatives' view on certain issues. This is something that further research could explore, in order to find ways to best help individuals suffering severe mental illness to find "asylum" in the community.

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