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Deinstitutionalization in Greece: Ethical problems

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The following paper is based on a Concerted Action which focused on the "Ethical aspects of deinstitutionalisation in mental health care" in 2001. It investigates the development and the ethical dilemmas posed by deinstitutionalization in Greece. This movement has recently undergone a very active phase but the transition from the traditional model of psychiatric care to the community based system unavoidably creates many ethical problems related to the professionals' attitude towards individual liberties, dignity and other fundamental rights of mentally ill persons. These problems exist not only in the level of the therapist-patient relationship but in the level of policy making as well as its implementation. Moreover, the paper deals with specific ethical problems such as stigmatisation and isolation in the community context, as well as the role of the family.

Key words: Deinstitutionalization, mental illness, ethical aspects.

Introduction

Mental health has always been an area triggering numerous conflicts and tensions, many of which are of a moral nature. Although for more than a hundred years psychiatrists have been practising their profession without being concerned with ethical and moral issues, following a long existing,

paternalistic tradition of how to serve the patient best, in the last few decades this has profoundly changed. Various developments in the societal context have played an important role in the shaping of new attitudes towards the patients as well as towards the notion of mental health and its social ramifications per se. During the last three decades, following the expansion of biomedical

ethics, which started in the 70's, the ethical dimensions of psychiatric care, have gradually received adequate attention and changes are beginning to be undertaken, even though psychiatric ethics still remains a bioethical "ugly duckling".¹ The increasing interest on ethical concerns has led to extensive writings, to Psychiatry training programs and texts such as the Principles of Medical Ethics in 1973 with annotations especially applicable to Psychiatry, as well as to the Declaration of Hawaii by the World Psychiatric Association in 1977.^{2,3} This shift in awareness has led to the corroboration of a view which had once been hard fought against but is today widely accepted: the view that science and ethics are closely interwoven and that modern Psychiatry cannot exist without reference to its ethical background and the inherent values, without the recognition of rights and duties or without the application of norms and rules which dictate respect to the legal and moral entity of the individuals concerned. This framework, which has been reinforced by the increased emphasis on human rights, including the rights of people with mental disability or incapacity⁴ does not refer only to the traditional hospital/asylum context but also to the modern movements of deinstitutionalization and rehabilitation: in the community environment the fundamental values which lay the foundation of ethical reflection in Psychiatry, i.e. trust, autonomy, privacy, care and justice⁵ acquire a new significance as they function in a different milieu. The above mentioned moral considerations which also include the inhuman character of long-term hospitalization, as well as the right of individuals with mental health problems to be integrated into society, along with financial and legal concerns, have not only been some of the major incentives for deinstitutionalization but have also led to serious ethical ramifications of this process in most of the countries in which it was implemented.

The historical background of deinstitutionalization in Greece

Since 1980, the term "deinstitutionalization" has been used in Greece to describe the integration of mentally ill people to the community. Similarly with

other countries, the transition was motivated by the need to face the distressing conditions of large psychiatric institutions, especially the violations concerning dignity, autonomy and privacy of the individuals. It was also driven by the need to decrease the high financial maintenance cost of such institutions.

When this movement started twenty five years ago, it had as its main target not to close down these institutions but rather to downsize them and to restrict their role in the care of mentally ill people. This process did not of course develop in a cultural and conceptual vacuum but emerged slowly as the product of various fermentations which took place in the field of Psychiatry in many countries and subsequently in Greece.

A brief overview of the history of Psychiatry in Greece would focus on three different phases of development:

- a. The practice of popular beliefs, which pre-existed to psychiatric services and later survived in parallel: these had been always related to religion as some churches and monasteries, following the Byzantine tradition of hospitality, used to admit a small number of insane people.⁶ We can also mention beliefs on the "evil eye".⁷
- b. The introduction of modern psychiatric practices and the training of mental health professionals: these followed the dominant model of European medical and University practices. Education of medical doctors who were interested in psychiatry, was widely dependent on studies and educational journeys mainly to European countries. These influences were reflected in legislation and in transfer of practices in Greece.⁸ The first law regarding mental health, Law Ψ MB of 1862, was heavily influenced by the French law on mental health of 1838. Decree 104 of 11.8.1973, another important piece of legislation, abolished Law Ψ MB, maintained hospitalization as the centre of mental health care system, focused on dangerousness but on the other hand introduced, for the first time, the possibility of voluntary hospitalization for mental patients.⁹ Finally, Law 2071 of 1992 harmonized Greek legislation concerning psychiatric care with European guidelines.

c. The foundation of psychiatric services: the first psychiatric hospital was founded in 1838 in the island of Corfu which was then under British control and the second one, "Dromokaition", was founded in Athens in 1887. These were the first examples of a development which took place in the first decade of the twentieth century along with urbanization, economic progress and industrialization of the country. A network of 9 hospitals was completed after the 2nd World War. Nevertheless, albeit the picture of the mental health institutions in Greece was not very different from that of the other European countries, the most important developments in the field of mental health took place much later than in the rest of Europe.

The psychiatric hospital of Leros (in the well-known Aegean island), the psy. hospital for children, of Daou-Pendeli's (near Athens) and the psy. hospital of Petra (at the mountain of Olympus), in their beginnings used to admit chronic patients referred to them mainly from the psychiatric hospitals of Athens and Thessaloniki. These heavily institutionalized patients constituted one of the main target groups of deinstitutionalization programs. The population of chronic patients in the totality of Greek psy. hospitals has greatly diminished, through a widespread network of community-based housing units, which has to achieve now its integration in community based psychiatric units of care and its financial survival. Since 2004 the psy. hospital of Petra-Olympus, and since 2006 the psy. hospitals of Corfou and Chanea (Crete) do not admit patients any more.

The landmarks

In the 70s and the 80s the experiences of Italian deinstitutionalization and French sectorization had an important impact to Greek Psychiatry but the major obstacle at that time was the lack of outdoor and outpatient services, the establishment of which being the main target in the late 70s for the deinstitutionalization of patients of major psychiatric hospitals.^{10,11} In the early 80s, despite the existence of some pilot programs, psychiatric in-patient care was mainly provided in public and

private mental hospitals. Apart from these pilot studies, neither community based mental health services nor psychiatric beds existed in general hospitals.^{12,13} Social and vocational rehabilitation, part of the deinstitutionalization movement, appeared in Greece in the middle of the 80s, although some earlier efforts had been done in the 50s, focusing on chronic patients of public psychiatric hospitals.¹⁴

The landmarks of the recent development of psychiatric care in Greece were the introduction of the National Health Service in 1983, the Regulation 815^{15a} (1984–1994) (EEC 1984) and the application of the "Psychargos" I and II^{15b} program of the European Union, which provided very important financial support to changes and progress realized in the years to follow. One of their main objectives was deinstitutionalization of long stay patients in mental hospitals, but in a short period, Greece also managed to make a considerable progress in community based mental health services and increase of psychiatric beds in General Hospitals.

The most recent law, enacted in 1999 (L.2716/99) provides extensively, among others things, for the development of halfway houses, nursing homes, hostels, supervised apartments, family foster care and other residential options that represent steps towards the goal of independent living as part of the deinstitutionalization and rehabilitation process. According to Section 1 of Law 2716/99: "Mental health care services are structured, organized, developed and functioning according to the present law on the basis of the principles of sectorization, community psychiatry, priority of primary care, extramural care, deinstitutionalization, psychosocial rehabilitation and social reintegration, continuity of psychiatric care as well as information and voluntary contribution of the community in the promotion of mental health". Emphasis has been given on development and improvement of the users skills with the application of social and professional rehabilitation programs. Thus, a replacement of institutional forms of care by a network of alternative preventive and therapeutic structures outside the hospital, could be gradually achieved.

The existing network of services of care and rehabilitation is functioning within Public Hospitals, University Hospitals and non-profit private organizations. Private clinics (estimated to reach a number of 30 on a national level in 2007), provide only indoor care and their beds are in majority occupied by chronic patients.

Although remarkable efforts have been made, the total number of outdoor services still remains insufficient. The programs of public hospitals deinstitutionalization in Greece, including the deinstitutionalization of Leros from 1989 to 1994 (Leros I and II, through the program "Psychargos" I and II, have led to the development of an important network of half-way houses and supervised apartments – 269 units, with 2695 residents and 3061 staff members.¹⁶

The primacy of outdoor care and prevention, recognized by Law 2716 of 1999 could be achieved through an effective application of sectorisation of mental health services (sectors of 250–300,000 inhabitants). To this day, outdoor services of care, psychiatric hospitals, psychiatric units in general hospitals and housing units in the community have not been coordinated through sectorisation, while financial problems heavily burden the progress of the reform.

The ethical dimensions of deinstitutionalization

The experience of deinstitutionalization in different countries and the transition from traditional to community based psychiatry which has promoted the "public health model", has yielded a number of problems and has created a variety of ethical ramifications as the psychiatrist acquires a more active role in the social network.¹⁷ Moreover, the principle of least restriction, one of the central ideas behind the process of deinstitutionalization which concerns the management of incapacitated persons provides a new prism through which their whole physical and psychological existence is being viewed. In the most recent Code of Medical Ethics in Greece, it is mentioned that psychiatrists have the duty to proceed to therapeutic interventions which restrict as little as possible the freedom of the person concerned.

Also, additional discoveries regarding the biological foundations of behaviour, have had considerable influence on the conception of mental health and consequently its ethical framework. It is well accepted that the therapeutic goals of psychiatry are best fulfilled only if considerations regarding the individual's dignity and autonomy are taken into account and under the condition that the patient's consent is being sought; it has been considered an abuse of one's own right of liberty and dignity to involuntarily place him to an institution, even for him own benefit unless the exact requirements of the existing legislation are being followed. However, the question arises whether it is ethically appropriate to enforce a patient to live in the community if he is not fit for this and to refuse him a sheltered environment. It should be pointed out here that in Greece, the network of halfway houses permits the existence of a gradual transition from hospital to the community and that the problem of homeless people is not yet as serious as in other countries, although, at least in the capital, the situation is rapidly changing for the worse.

Currently, in Greece, deinstitutionalization is undergoing a very active phase with many ethical ramifications which can be found in two different levels: firstly in the level of inter-personal relationship between the therapist and the patient (the term client is not broadly used in Greece) as well as in the level of mental health care provided in the community context.

The role of the therapist and the environment in which the patient and the therapist co-exist, have been described as two of the most important factors in the formulation of ethical questions.¹⁸ The success of deinstitutionalization depends a lot on the human factor and especially on how mental health professionals grasp the notions of autonomy and beneficence. Moreover, the way in which professionals view demented patients has many ethical implications regarding the notions of personhood and personal identity.¹⁹ In the Greek medical context, where the interpretation of the Hippocratic tradition has led to the emphasis of the notion of duty in a way which has nurtured deeply paternalistic attitudes, a provision of care which takes seri-

ously into consideration the notion of individual autonomy is not self-evident. Paternalism in Greece has prevailed for a long time as an extreme form of the notion of beneficence and despite the fact that the Greek Constitution safeguards respect and protection of individual value as well as each citizen's right to develop freely their personality, for a very long time relationships in the medical setting have followed a more austere and traditional pattern based on "medical authority". According to the American bioethicist, Robert Veatch, the development of autonomy presupposes abundance of financial resources, technological scepticism and liberal individualism emphasizing the importance of autonomy in relation to the Hippocratic tradition.²⁰ The fact that Greece did not fulfil these conditions could indeed be a reason why paternalistic attitudes survived not only in the psychiatric but in the general medical context. Until the 70's these attitudes were reinforced by the fact, uncontested by the social environment, that medical doctors negotiated with the family rather than with the patient himself.²¹

Although similar attitudes have been gradually changing and the existing Patients' Rights legislation safeguards autonomy, provision of information and consent, these issues continue to constitute in practice some of the main ethical problems in the process of deinstitutionalization.

Results of concept mapping in Greece

In 2001, UMHRI (University Mental Health Research Institute) participated in a BIO-MED program of the EU on "Ethical aspects of deinstitutionalisation in mental health".²² A limited sample of patients, family members and professionals was interviewed according to the "concept mapping" method²³ where the opinion of various stakeholders regarding their perception of "good care" were asked. These stakeholders were people with mental health problems, family members, professionals, policy makers and the local community. In each participating country 86 statements of what "good" mental health care is, were proposed to representatives of the five stakeholder groups, who first prioritized the statements on a scale of

importance and organized them into clusters. The data collected were statistically processed by the Trimboos-Instituut which was the central coordinator of the project.²⁴ The results concerning Greece could be summarized as follows: Patients and professionals working in the deinstitutionalization field believe that priority should be given to treating the patients with respect, to cooperation, to the accessibility of mental health services and to the avoidance of coercive treatments. Other priorities were believed to concern adequacy of a crisis response, involvement of carers, accessibility of rehabilitation services, involvement in the evaluation of mental health services and support for the neighbourhood. Thus, good care was in general considered synonymous to a respectful attitude of professionals, trust and confidence, individually tailored care, encouragement of responsibilities and active participation in decision-making. The respectful relationship between patients and care providers especially, was considered by all as the most important aspect of good care. Nevertheless there were some interesting differences between the participating countries: in the Netherlands, for example, respondents placed more emphasis on the role of good care in rehabilitation, whereas in Greece and Belgium more importance was ascribed to the effectiveness of care. Good care, however, is also supposed to mobilize community support mechanisms in parallel with medical treatment. For example, treatment of relapses of patients in halfway houses has been trying to avoid reproduction of the "revolving door" phenomenon.^{24,25}

Stigmatization

Schizophrenia has always been associated with a significant amount of stigma all over the world: studies suggest that the majority of citizens in the United States²⁶ and many Western European nations have stigmatizing attitudes about mental illness.²⁷ In Greece there are many folk beliefs, stereotyped ideas and scornful expressions about schizophrenia generated by strong religious and cultural values. These notions are mostly empirically noticeable in

some aspects of interpersonal relationships in everyday life, the mass media and the civil laws.^{28,29}

Despite the Greek origin of the words "stigma" and "schizophrenia", stigma attached to this severe mental illness has not been adequately studied in Greek society. Up to 1980, there were very few studies on people's perception of mental illness, mainly among relatives of the mentally ill conducted in 1964 and 1977.^{30,31} In the general population, two studies^{32,33} showed some changes in public attitudes and beliefs about the various causes of mental illness. The majority of the respondents in the 1964 study believed that the main cause of mental illness was "poverty" and "bad socioeconomic conditions", whereas the 1977 study revealed that "everyday life stress" was the main cause and only older individuals expressed the view that mental illness is inherited. In the second study, in terms of seeking help, it was found that only young respondents raised and living in Athens would seek help from a psychiatrist in the case of a major psychological problem, while the rest of the population preferred other traditional means of seeking help such as priest, folk healers, relatives, etc.

In 1980, public attitudes towards mental illness were explored and the majority of lay respondents were found to be rejecting and afraid of people with mental illness, with only younger and better educated people expressing humanitarian views and tolerance of any deviant behaviour.³⁴ A decade later, respondents from the same cohort were found to be more positive towards social integration of people with mental illness and against social discrimination and restriction of mental patients.¹³ Madianos et al attributed this improvement to social changes that took place in Greece at the time and to the crucial role played by community mental health prevention programmes.

In 2001, the University Mental Health Research Institute (UMHRI) joined the World Psychiatric Association's international programme "Against stigma and discrimination because of schizophrenia" and has undertaken a number of research and training initiatives since then. Congruent with this, it conducted a national survey on the general population's knowledge about schizophrenia and its at-

titudes towards the people who suffer from it.^{35,36} The results demonstrated that lay people aged over 65, of a lower educational level and social class, living in semi-urban/rural areas, endorsed the most stigmatising attitudes towards people with schizophrenia (PWS). Furthermore, the degree of desired social distance from a person with schizophrenia was found to increase, as the intimacy necessitated in the interaction increased as well. In addition, and quite surprisingly, the Greek public was shown to be more reluctant to have someone with schizophrenia as a colleague rather than as a friend. Concerning comparisons of public attitudes towards people with mental illness and other groups vulnerable to stigmatisation (e.g. immigrants, HIV patients, etc) it was revealed that Greeks tended to stigmatise people with schizophrenia the most, even more than serious law offenders. The implications of these findings can be better grasped, if one considers the responses given to questions addressing attitudes towards the operation of small group homes in the community accommodating PWS. In particular, while 51% of the sample was in favour of such a prospect, 20% objected to it, while 57% of the opposers claimed that they would actively resist such a development. In terms of their knowledge about schizophrenia, the Greek public was found to be either poorly informed or misinformed. The vast majority of respondents regarded PWS as dangerous (75%), with split personalities (81%) and being incapable of employment (83%). Furthermore, they tended to be oblivious of the genetic factors in the etiology of the disorder, as 1/3 of them attributed it solely to environmental and psychosocial agents. Interestingly, 66% of the respondents reported that television was their primary source of knowledge about schizophrenia.

Building upon the aforementioned survey findings and existing literature,³⁷ a subsequent investigation of the role of media on promoting the stigma attached to mental illness was carried out.³⁸ The study examined the ways whereby mental illness and people suffering from it are represented in Greek newspapers and magazines. Specifically, the stigmatising articles were found to have significantly larger sizes and more memorable layout than the neutral or the

anti-stigmatising ones. Moreover, only a minority of the mental health articles were written by mental health experts; most of them did not entail any scientific research; and while half of them had incorporated comments made by experts, PWS could not share their experiences and raise their concerns in these articles. In fact, in the majority of them, they were portrayed as being violent and dangerous. It is, therefore, safe to claim that schizophrenia is highly stigmatised in print media, where stereotypes of violence, danger and unpredictability are prevalent.

Furthermore, stigma has been proposed to be a multidimensional concept entailing faulty beliefs (stereotypes), unfavourable attitudes (prejudice) and negative behaviours (discrimination).^{39,40} It has also been shown to affect the lives of both the people who suffer from mental illness as well as their families; in areas such as interpersonal relationships, daily activities, media, legislation, and interactions with health professionals.⁴¹⁻⁴³

In several European studies, mainly in Greece and Portugal, it is shown that families are very important for psychological as well as financial support of patients living in the community. Indeed, a significant number of mentally ill patients, with diagnoses of schizophrenia and other severe psychiatric illnesses, are living with their families, usually with their parents. Although during the past decades there has been a great shift in the attitudes of families towards mental illness and the ways families respond to their mentally ill member, from being highly isolated from the rest of the community and embarrassed and ashamed about it to being more open and integrated, psychological and financial burden still remains high.

In an effort to reduce the family burden and stigma associated to mental illness, SOPSI (Family Association for Mental Health) was founded in 1993 by relatives of people with mental illness. Its main objectives are to promote support for the mentally ill and their carers, improve care and welfare, provide information about mental illness and the availability of mental health services, improve public awareness about mental illness and reduce the stigma, and the discrimination against the mentally ill and their families. In the beginning, mainly due to stigma it was

difficult for family members to join SOPSI. However, after time and effort from families and mental health professionals, SOPSI has become a highly active families association with more than a thousand members in Athens. Today, a well-cooperated and organized network of family associations has been established across Greece forming a federation under the name of POSOPSI (Panhellenic Federation of Family Associations for Mental Health).

The precise effectiveness of interventions and efforts undertaken against stigma remains to be investigated; however, it is encouraging that there is a universal endeavour to combat psychiatric stigma and Greece actively participates in this effort.

Conclusions

At present, apart from the essential problem of maintenance of a sufficient material infrastructure, what is mostly needed is a change of mentality and the attitudes of health professionals, especially of those who, in the past, had been working in large institutions and who are now facing the challenge of working in a completely different environment. The task of enabling mentally ill chronic patients to realize their potential, to use it and to wish to live outside the mental hospital is very difficult and complicated.

In psychosocial rehabilitation and reintegration, however, considerations arise in an additional level: in the level of community and society, of strategies and policies. Most often, policy makers do not pay the attention needed to the ethical dilemmas raised and deinstitutionalization is not an exception to this rule. Nevertheless, decisions made in this level aim at the wellbeing and at the good quality of life of the individual. The exact content of these notions as well as the criteria according to which this content is measured, are determined according to a series of value judgements which are materialized through the setting of priorities. Decision makers in Greece have to realize that ethical problems exist not only in the level of the therapeutic relationship between the patient and the person who provides care, but in the level where today the genesis and the rapid development of new relationships between medicine, public health, ethics and human rights are taking place.⁴⁴ The responsibility of those who formulate policies

to be followed is an ethical responsibility of a dual character: to protect and promote mental health but also to protect and promote human rights of a most vulnerable group of the population, to evaluate their quality of life, to ensure access to health care services and to offer job opportunities. This is well reflected in modern legislation regarding protection of human rights: for example, General Comment 14 of the Commission of the International Covenant on Economic, Social and Cultural Rights. The right of health should be approached through 4 parameters, i.e. availability of services, accessibility, acceptability and quality of care. Mental health which, compared to other forms of care, is being neglected, is mentioned as an example of dysfunction of all efforts to materialize the right to health.^{45,46}

Deinstitutionalization in Greece has been a long and painful, but quite successful so far and still continuing journey, whose most difficult part for the pa-

tient is not getting out of a psychiatric hospital but being re-integrated into community. Nevertheless, the very nature of deinstitutionalization which is based on a different perception of mental illness makes plausible the fact that the road is full of ethical pitfalls, the most dangerous of which is to focus on the idea and to forget the persons and what all this means to them. During the deinstitutionalization process it is important to make the underlying values sufficiently explicit, to increase awareness and to integrate ethical principles in regulatory measures. Moreover, education of professionals in bioethical issues should be enhanced towards the above mentioned directions.

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Αποϊδρυματισμός στην Ελλάδα: Ηθικά προβλήματα

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Η εργασία αυτή βασίστηκε στην ανταλλαγή απόψεων και στα αποτελέσματα του Ευρωπαϊκού Προγράμματος "Ethical aspects of deinstitutionalisation in mental health care". Εξετάζει την ανάπτυξη της αποκατάστασης στην Ελλάδα και τα ηθικά προβλήματα που θέτει. Παρά το γεγονός ότι η αποκατάσταση αναπτύχθηκε σημαντικά τα τελευταία χρόνια, η μετάβαση από το παλιό σύστημα ψυχιατρικής φροντίδας στο εξωνοσοκομειακό δημιουργεί πολλά προβλήματα, ιδιαίτερα σε ό,τι αφορά τη στάση των επαγγελματιών ψυχικής υγείας απέναντι στις ατομικές ελευθερίες, την αξιοπρέπεια και άλλα θεμελιώδη δικαιώματα των ψυχικά ασθενών. Αυτά τα προβλήματα δεν υπάρχουν μόνο στο επίπεδο θεραπειών-ασθενών αλλά και στο επίπεδο λήψης πολιτικών αποφάσεων. Το κείμενο πραγματεύεται επίσης ειδικά ηθικά προβλήματα όπως το στίγμα και η απομόνωση στο πλαίσιο της κοινότητας ή τον ρόλο της οικογένειας.

Λέξεις ευρητηρίου: Αποϊδρυματισμός, ψυχική ασθένεια, ηθικές πλευρές.

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