The impact of mental health community services on quality of life of adults with chronic mental distress. Results of a Qualitative Study

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Introduction

Community Care Policy has been implemented for over 40 years in Northern America and Western Europe. However, its implications on people with mental distress have not always enhanced the quality of their lives (QOL). Although cultural psychiatry challenges assumptions of universality the majority of questionnaires used in clinical trials are developed mainly in English-speaking countries and imposed the values and principles of Western culture, therefore, qualitative methods should focus on examining how different individuals perceive quality of life and the way they feel about their role in society. Despite the call for more qualitative research in the field of mental health, there is still a small amount of relevant studies which used qualitative method in Greece. This report presents a summary of qualitative outcomes of a bigger PhD project which utilized a mixed method, a specific-disease quality of life (QOL) scale, the Lancashire Quality of Life Profile (LQOLP) (Oliver, 1994), which was translated and culturally adapted in the Greek context by the author, and semi-structured interviews, in order to explore a) objective and subjective well-being indicators, and b), community mental health service users' views about 'what quality of life' means for them.

The shift from institutional to community care in Greece.

European psychiatric reform processes are driven by broad social, cultural and scientific trends and this has been the case during the second half of the 20th century. At a cultural level, the concepts of cure and chronicity changed, giving focus on the enhancement of quality of life and the functional abilities of the individual. In Greece, the signal for reform was given externally by the administrative intervention of European social policy and was not the outcome of pressure on the part of social and professional groups, as was the case in other European countries. Before the 1980s there had been no systematic study of the picture of health and social care

sector, and services were developed at a very slow pace and without a rational planning system. Munday (1996) characterized the type of welfare system in Greece as 'Latin Conservative' with the family and the private sector having the main responsibility for social care. Despite the fact that family ties are strong, families had the tendency to abandon their vulnerable members with long-term disabilities, including those with mental distress due to existing stigma and discrimination against people with chronic disabilities (Asimopoulos 1998:44). The first attempts to implement the new policies in Greece took place during the period 1984-1996 and aimed, a) to improve living conditions of existing mental health hospitals, b) to create extra-psychiatric wards in general hospitals and c) to design mental health services in the community (Madianos 2000). Important factors which created obstacles during the first years of the reform were: Complicated bureaucratic procedures, which caused a long delay in establishing Community Mental Health Centres (CMHCs), lack of any public campaign, in order to inform the general public about the rational and the aims of the reform, and the complete absence of qualified professionals with training in social and human sciences. Despite the above limitations, from 1998 up to date, nationwide there has been a decrease of 66.5% of the remaining asylum residents, and there are 2500 community care residential facilities (hostels, sheltered apartments, etc) (MoHaSS, 2011). However, a lot of changes still need to be made at a political, clinical and cultural level, in order to ensure that people with mental distress receive the support that they deserve.

Methodology of the study

This analysis was part of a broader investigation of the way in which, adults with chronic mental distress perceived different aspects of their lives. Potential respondents should have a diagnosis of a severe mental disorder, with or without previous short-term hospitalizations, and their age should range from 18 to 55 years. The settings were 2 CMHCs supervised by the Medical School of the University of Athens. 44 people participated in the quantitative part of the study and from those, 22 service users from both settings were invited to talk in more detail about the quality of their lives. For the analysis of the qualitative findings the material from the semi-structured interviews was coded and thematically categorized (Fielding, 1993). The qualitative findings were also cross-validated with the quantitative results of the

study, in order to enhance validity and reliability of the study. Validity in qualitative method was also ensured via looking with scrutiny at the individuals' messages (Silverman, 2005).

Results

Participants' involvement in the CMHCs: a) enhanced their social relations and b) improved their sense of autonomy and self-determination.

a) *Participation in the CMHCs enhanced Social Relations*

Results drawn from the individuals' responses indicated that the relationships domain was a key domain in their lives. In particular, participants' common messages elicited that mental distress has affected their ability to maintain their previous social networks and that before their involvement in the CMHCs, they experienced feelings of social exclusion. Almost all noted the importance of having friends. A female participant 29 years old, who had been one month a member of the CMHCs at the time of the study, said:

> *'Before coming here, I had no friends at all. Here I made some. We discuss our problems and this helps…'*

Another female participant, 27 years old, explained how alliance among the group members has worked positively for her:

> *'Here, I can share my experience with others. Group sessions here, help me because each one of us expresses his opinion, so we learn from each other and we empathize with each other. Besides, when someone makes progress, this is encouraging for the rest of us.'*

A male participant 40 years old, who came from a small island and he moved to Athens in order to have access to proper mental health care talked about the stigma attached to mental distress in his local community, which caused him exclusion from his family of origin and previous social networks:

> *'Since I got ill, my friends and family do not want me. They do not understand that I can only be bad to myself and not to other people. Here, I found people who care for me'.*

a) *Participation in the CMHCs enhanced sense of autonomy and self-determination*

Within the qualitative interviews participants were encouraged to talk about how independent they felt and how they perceived autonomy. Even if they had specific skills for everyday life, there was a long-term dependency on the mental health care system and on their primary carers. A male participant commented:

> *'Autonomy means to be independent, I am not independent; I do not have my own income, my family supports me financially, and I applied for the welfare benefit…Besides, I cannot make plans for myself. I must follow doctors' suggestions about issues that concern me.'*

Emotional and practical dependence on primary carers were indicative in many responses. A female participant said:

> *'My family receives the welfare benefit on my account.*
> *My mother pays all the bills. I am a burden on my family.'*

It was felt that some participants had never been given the opportunity to take responsibility and make decisions for themselves before their involvement in the CMHCs. Their participation in the group therapy sessions and the structure of everyday program helped them to start taking decisions for themselves. A male participant, who has been a mental health service user for 11 years, describes below how, being a member in the CMHCs enhanced his sense of autonomy and self-determination:

> '*Coming to the Rehabilitation Centre helped me a lot. I discuss my problems; my opinion can be heard'. The most important thing is that since I have started coming here, pills have been reduced a great deal; I reached the point where I am searching for a job; something that I couldn't even imagine before. Now I try to go out for coffee with friends; I used to stay indoors all the time.'*

Discussion

Qualitative findings in the present study elicited that the effect of the CMHCs in the domain of social and personal relationships was remarkable. Most of the participants mentioned that their involvement in the daily community programmes enabled them to create new friendships. In addition, the alliances which they had developed with other members of the same programmes gave them the opportunity to discuss their thoughts and feelings about how their mental health problems had affected their life and personal choices–an important process which might help some people adapt to their present circumstances and potential losses (Oliver *et al.,* 1997). Sharing thoughts and feelings with others seemed important, especially because of the cultural

'covering' tradition which still characterizes Greek culture, regarding issues, of 'taboo' such as mental distress (Madianos, 2000). In contrast to the quantitative QOL measure, semi-structured interviews provided a deep understanding of the impact that the CMHCs had on service users' enhancement of their social networks.

The fear of self–determination might be a result of participants' involvement in a mental health care system which did not work under the principles of 'empowerment' and restricted them from making their own life plans (Chamberlin, 1997; Giftaki & Kakogianni, 2005). Although the quantitative QOL measure utilized in the present study, provided important scores with regard to global well-being, qualitative results showed that participants were highly dependent on their doctors' views regarding issues that had to do with their therapy, as well as with their life choices. These issues influenced negatively the way they perceived their QOL. Moreover, cultural characteristics which had not been addressed by the QOL measure emerged during the interview process, when participants referred to their high dependence on their family of origin. These findings confirm the fact that Greek family ties still remain strong (Asimopoulos, 1998), but at the same time, the role of informal carer, may be a source of stress, and influence the QOL of other members of the family, mainly women.

Any reader who is familiar with mental health research will recognize that there are considerable difficulties in obtaining a sample truly representative of the vulnerable populations who live in the community. The main contribution of this study was the use of a qualitative method in order to assess the quality of life of people with mental distress in a Greek context. Knowledge of cultural concepts of an ideal quality of life is an essential precondition for the assessment of quality of life in a given culture (Saxena, 1994). It is very important to take advantage of the European experience and adapt the reform respecting the cultural and social characteristics of Greece. Finally, it is necessary when designing mental health care interventions to take seriously into account the service users' views.

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