BIOGRAPHICAL TRAJECTORIES OF PEOPLE STRUGGLING WITH SEVERE DISTRESS: MAPPING THE SOCIAL DETERMINANTS OF RECOVERY IN PSYCHOSIS[1]

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During the last decades, there is increasing acknowledgment of the contribution of socioeconomic factors in the development and course of psychosis. This paper presents findings from a biographical study examining the role of social parameters and processes in the biographical trajectories of people with psychotic experiences. 27 biographical narrative interviews were conducted with individuals who experience severe distress, have received diagnoses of psychotic disorders and have been in contact with mental health professionals and services. The biographical narratives elicited were subjected to several layers of analysis, resulting in hermeneutic reconstruction of each narrative as well as the formation of groups and types of biographical trajectories of distress. In this paper we present one of the two groups of biographical narratives, the narratives in which participants recognize, own and attempt to manage their distressing experiences, and seem to be in a process of recovery. The main features of this group of narratives are the free-flowing reflexive narrative style, depicting the emergence of psychosis as a point of biographical disruption, references to various adverse experiences in childhood and adolescence, early acknowledgment and community management of distressing experiences, and finally continuing participation in interpersonal relationships and social networks. Participants in this group can be subdivided into two types, those who position themselves as struggling with severe distress and those who struggle against the biomedical model and the mental health service system, referred to in the literature as 'users' and 'survivors' respectively. We discuss the factors that enable biographical trajectories of recovery, demonstrating a dialectical relation between on the one hand professional institutions, knowledges and practices and on the other social networks and popular discourses on mental health as determining factors of a person's biographical trajectory with regard to severe distress.

Socioeconomic factors in the development and course of psychosis[2]

The role of socioeconomic factors in the development of psychotic disorders has been extensively documented. Starting from the early studies elucidating the uneven distribution of severe mental disorders in the socioeconomic status hierarchy, a large corpus of epidemiological studies have demonstrated the role of socioeconomic disadvantage, poverty, homelessness, urban upbringing, migration and minority status in the development of psychotic disorders (Morgan, McKenzie, & Fearon, 2008). There has been growing evidence for an association between childhood traumatic experiences, such as abuse, neglect and victimization, with the subsequent emergence of psychotic experiences (Read, Fink, Rudegeair, Felitti, & Whitfield, 2008) and more recently research has focused on the contributing role of adverse childhood experiences, including poverty and inappropriate living conditions, family disorganization and conflict, separation from parents, as well as problematic early attachment experiences (Bentall et al., 2014; Tienari & Wahlberg, 2008). Research has also highlighted the mediating mechanisms, for example forms of socialization, access to resources, social support etc., through which objective socioeconomic indicators affect mental health (Eaton & Muntaner, 1999), as well as the relation between social structural factors and personal understandings and strategies of acting subjects (Dillon, 2011).

The role of socioeconomic factors in the course of psychosis has been much less investigated. The initial assumption, following the Kraepelinian paradigm, that psychosis is a chronic condition with deteriorating course was left unchallenged for the largest part of the 20th century. A number of longitudinal studies in the last decades have established that the course of psychotic disorders is highly variable, ranging from progressive deterioration to complete restoration of functioning, with various combinations of periods of intensified mental distress and periods of partial or full remission of symptoms for the majority of sufferers (Davidson & Roe, 2007; Slade, Amering, & Oades, 2008; Warner, 2009). The International Study of Schizophrenia, coordinated by the World Health Organization, traced recovery from psychosis over 25 years in several countries and validated once again the findings on the heterogeneity of the course of psychosis (Hopper, Harrison, Janca, & Sartorius, 2007). Moreover, it contributed, together with other studies, to identifying factors that influence the course of psychosis. Age of onset, type and intensity of symptoms and prior levels of functioning, referred to as 'premorbid adjustment', seem to correlate with the course of psychosis (Hopper et al., 2007; Jeppesen et al., 2008). The early trajectory of psychotic experiences has been found to predict long-term course (Hopper et al., 2007) and the time between emergence of psychotic experiences and contact with mental health services, referred to as 'duration of untreated psychosis', predicts negative outcome (Jeppesen et al., 2008; Marshall et al., 2005). Both findings

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[2] We would like to point out here that we use the term 'psychosis', rather than the related contemporary diagnostic categories – e.g. 'schizophrenia', 'delusional disorder', 'bipolar disorder' – as a term that designates the specific experiences of distress but does not subscribe to the assumptions that underlie contemporary diagnostic classifications. We recognize, though, together with others (British Psychological Society, 2014) that the use of the term 'psychosis' as a more progressive alternative is not without problems.

point to the importance of the way distress is initially managed for its subsequent development and has encouraged early detection and intervention initiatives (Marshall & Rathbone, 2011). The consistent finding of more favorable outcome of psychosis in developing countries has led to discussions of possible positive contribution of family involvement and extended family support, community cohesion and social integration, less stigma due to popular beliefs regarding distress, employment opportunities through accommodating work regimes and availability of various community treatment options (Hopper, 2008). Although less studied, there are indications that in developed countries adverse social conditions, such as unemployment, poverty, homelessness and social isolation negatively impact on the course of psychosis (Warner, 2008). This is also echoed in the growing acknowledgement of the role of social support in the course of psychotic disorders (Anderson, Laxhman, & Priebe, 2015; Bebbington, 2013). Despite increasing research on the factors influencing the course of psychosis, the contributors to the International Study of Schizophrenia note that the sociocultural factors that account for the major discrepancies in the course and outcome of psychosis between the study centers are yet to be identified and conclude that "future studies will require both qualitative and quantitative methods to explore the characteristics of environment that promote recovery" (Harrison et al., 2001: 515).

The acknowledgment in the scientific literature that people with psychotic experiences can recover, in conjunction with testimonies of recovery and pressure from the user movement, brought to the foreground the notion of recovery from severe mental distress, which has flourished in the last two decades and even became the guiding vision for mental health services in a number of, mainly English speaking, countries (Slade et al., 2014). Notwithstanding differing, and even opposed, understandings and definitions of recovery (Bellack, 2006; Davidson, Schmutte, Dinzeo, & Andew-Hyman, 2008), the bourgeoning literature on recovery attempts to identify the factors that enable people in severe distress to live a fulfilling life, with or without the distressing experiences. Central tenets of recovery seem to be hope and optimism for the future, empowerment and control over one's life, rebuilding positive personal and social identities, and finding meaning and purpose in life (Onken, Craig, Ridgway, Ralph, & Cook, 2007; Wallcraft, 2005). Having supportive relationships with family, friends and intimate partners is considered crucial for recovery, as well as engaging in socially valued roles and activities and having a sense of belonging to communities, in the mental health field and beyond (Leamy, Bird, Le Boutillier, Williams, & Slade, 2011; Tew et al., 2012; Topor et al., 2006). Recovery takes place beyond the mental health service system, in the person's everyday life, interpersonal and social networks and through mobilizing personal resources and various self-care strategies. Mental health services have an important role to play in facilitating recovery through fostering the elements that promote recovery and orienting service users to networks and resources that they can utilize in their recovery journey. In the last decades there has been considerable discussion around creating, maintaining and evaluating recovery-oriented mental health services (Anthony, 2000; Davidson, O'Connell, Tondora, Styron, & Kangas, 2006). Notwithstanding the value of the recovery approach for fundamentally transforming the conception of severe mental distress and its

management, the recovery model, especially as it has been coopted by the scientific community and utilized in mental health policy, is permeated by the ethos of liberal individualism. It is conceived as an individual journey of personal development, whereby the person as an active agent takes on the responsibility for the care of their self. Interpersonal relations, social support, covering basic needs, provision of mental health care and access to social roles and social participation are important, but they function as resources for individuals to use in their quest for personal change. In this model, the structural causes of distress are occluded, so that people are oriented towards individual actions for personal change and away from collective action for social change (Harper & Speed, 2012).

A biographical narrative study of lives marked by severe distress - Method

Rationale

The aim of the study was to examine the role of social factors in the biographical trajectory of people with experience of psychosis. Theoretically, the study draws upon social constructionism, hermeneutic sociology and symbolic interactionism, dialectical methodology and critical realism (Chtouris, Zissi, & Rentari, 2015), as it explores the interconnections between the micro-level of subjective experience and the lived world of individuals and the macro-level of the social and historical realities they are part of. At the core of this theoretical frame is the understanding of social reality as both objective, consisting of symbolic and social worlds, and subjective, consisting of social meanings and interactions taking place within specific social structures (Berger & Luckman, 1991). Methodogically, these theoretical paradigms have been supported by a turn to a qualitative investigation of subjective experience, through the use of grounded theory, interactional analysis and, mainly in the German speaking world, the biographical approach.
Following these theoretical and methodological principles, the study focused on the life narratives of people whose biographical trajectories were derailed from the normative social and cultural prescriptions, were marked by painful life events and were placed under institutional control. We aimed to investigate the factors that turned adverse life experiences to what in the biographical approach is referred to as 'dependent biographical trajectory' (Schütze, 1999), that is to say a life course, whereby the specific experience of suffering becomes central in shaping one's life and identity.
The study examines two phases of this biographical trajectory: The first phase concerns the trajectory up to the emergence of psychotic experiences, covering experiences and life events from early childhood to the first years of adulthood, when psychotic experiences most commonly appear. The second phase concerns the period from the emergence of psychotic experiences until the present time, that is to say the biographical trajectory within psychosis. This focuses on the experience of psychosis, its effects on the person's life, its management through contact with mental health professionals and services, and finally the coping strategies the person has adopted.

It was expected, on the basis of the relevant literature, that people's biographical trajectory would be differentiated depending on the person's position in social stratification and that the analysis would culminate in socially differentiated patterns of biographical trajectories towards and within psychosis.

The biographical approach

The study methodologically adopted the research paradigm of the biographical approach (Chamberlayne, Bornat, & Wegraf, 2000; Miller, 2000). The biographical approach focuses on the historically formed and socially and materially constituted subjectivity, examining on the one hand the processes through which social conditions and processes are inscribed in the personal history of subjects and on the other the ways in which subjects perceive and manage these social processes.

The biographical narration is a complex text, which can be read in several layers: It provides information on the subject's *life course*, that is to say, the social conditions and events that have influenced their life, as well as on their *lived life story*, the ways in which the subject experienced, understood and acted during their life course. It also provides information on the subject's *biography*, that is to say, the way in which, from the perspective of the present, the narrator selectively constitutes their past and thus orients towards their future. It refers to the *socially available resources*, from which the narrator draws and through which the biographical narration has been formed. It refers to the narrator's *subjectivity*, that is to say, the personally distinctive way in which the subject incorporates the social in order to interpret their life and the way they are subjectively constituted within it, both at the level of their narrated life course and at the level of the narrating act. Finally, it refers to the *interactional context* within which the biographical narration is produced.

Generation of research material

27 biographical interviews were conducted with individuals self-identified as having psychotic experiences. Participants' age ranged from 23 to 49 years. They had received one or more diagnoses of psychotic spectrum disorders, mainly schizophrenia, bipolar disorder and schizoaffective disorder. In order to ensure a maximum internal differentiation of the sample, both in terms of participants' socioeconomic position and in terms of their therapeutic itineraries, participants were recruited from several sources. More specifically, 12 participants were recruited from public in-patient mental health units of the Psychiatric Hospital of Thessaloniki, 5 participants were recruited from public community services of a regional town, and 10 participants were recruited from advocacy organizations and self-help groups in Thessaloniki and Athens.

In all cases one biographical interview (Atkinson, 1998; Wengraf, 2001) was conducted with each participant, by one of the two authors. All ethical principles were adhered to both in the process of recruitment and during interviewing participants. Participants were fully debriefed prior to their participation, were provided with a study information sheet and signed a consent form. The interviews lasted from 30' to almost 120'. The interviews started with a request to participants to recount their life

in chronological order, and the interviewers were subsequently guiding the course of the narration with questions aiming to cover important aspects of participants' lives.

Analytical processes

Given that there are several interrelated layers at which a biographical text can be analysed, each layer requiring different analytical tools, a combination of approaches were used for the analysis of the research material:

Analytical tables were constructed, which schematically presented elements of participants' life course along the study's theoretical and analytical axes. These included socioeconomic origin, place of upbringing, adverse experiences with primary caregivers, age and type of first contact with mental health services, diagnoses given, types of treatment received etc..

Chronologies were composed for each interview, containing a thematic summary of the participant's life course through each life stage.

Structural textual analysis was performed on each interview, through line-by-line coding of thematic content and textual type, examining the sequential organisation of topics, the importance given to certain topics and the silencing of others, combined with the strategies for the depiction of specific aspects of one's life and for self-presentation employed in the narrative.

Detailed reflexive *micro-analysis* was conducted on each interview, tracing the development of the biographical narrative, following the principles of reconstruction and sequentiality (Rosenthal, 2004). This iterative process generated hypotheses regarding the biographical importance of life events and conditions as well as the orientation of the narrator regarding their life. Both the structural textual analysis and the micro-analysis of the biographical texts enabled us to move from a depiction of the subject's life course, the chronological depiction of objective life events and conditions, to examining their lived story and biography, that is to say, the way participants form their life story from the perspective of the present, as well as the way they constitute their subjectivity both as narrators and in their narrated story.

Through a collaborative iterative process of comparing and combining the elements of the narrative highlighted in the previous analytical phases, we entered a phase of *hermeneutic reconstruction*, whereby the central parameters of each biographical narrative were identified and their dynamic relationship explored, culminating in textually and conceptually dense accounts of each biographical trajectory. It became clear, though this process, that these dependent biographical trajectories are shaped by a conglomeration of factors, related to broader sociohistorical conditions, the narrator's socioeconomic origin, life conditions and events as well as socially and institutionally available discourses, which dynamically interact, while none can be singled out as crucial.

The last phase entailed the systematic comparison across biographical interviews, culminating in the formation of *groups and types of dependent biographical trajectories*. This enabled a dialectical synthesis, reaching a higher level of conceptual abstraction regarding the

factors that shape differentiated trajectories towards and within psychosis.

Groups and types of biographical trajectories marked by severe distress

Through the analytical process it became clear that the biographical narratives elicited fall into two groups, which are distinctive in terms of narrative form and style, depiction of life events and experiences of distress, therapeutic itineraries and constitution of the self. Each group was further differentiated into types of biographical trajectories of distress. The main axis for organizing the material was not the life course narrated, that is to say the way conditions and events are depicted in the narrative, but rather the narrative biographical constitution, that is say the way in which the narrator's biography is constructed from the perspective of the present. More specifically, our main analytic axis was the positioning of narrators vis a vis their experiences of distress, in other words the constitution of the self with regard to the psychotic and psychiatric experiences.

Using the position that the participants assume vis a vis their experiences of distress, narratives could be divided into two main groups. The narrators placed in the first group systematically distanced the psychotic experiences from their self, using a variety of strategies ranging from concealment and undermining to utter repudiation. These participants do not describe experiences, thoughts and feelings that constitute their distress. Instead they use vague expressions indicating mental suffering, they offer their psychiatric diagnosis as an indication of the kinds of problems they face, or, in some cases, they deny having any unusual and distressing experiences at all. Other participants, who were placed in the second group, produce rich descriptions of their psychotic experiences, which they narrate as bizarre, distressing and uncontrollable experiences that they faced and are still struggling with. It seems that they recognize, own and attempt to make sense of their experiences of distress. These two approaches to distressing experiences have been discussed as 'sealing-over' and 'integration' recovery styles respectively, with integration recovery style linked to better course of psychosis (Tait, Birchwood, & Trower, 2004). In this paper we will discuss the second group of biographical narrations.

The narratives in this second group indicate that their narrators are in a process of recovery. Neither the narrators nor the interviewers use the concept, as it is not in widespread use in the mental health field in Greece. However, participants in this group seem to own their distress and to attempt to make sense of it and manage it, and they are engaged in an ongoing struggle to build a reasonably fulfilling life with their distressing experiences, in line with the processes of recovery, as delineated in the literature (e.g. Bellack, 2006; Davidson & Roe, 2007).

Owning and living with psychotic experiences: Biographical trajectories of recovery

In the group of participants who recognize and own their distressing experiences we included 12 of the 27 people interviewed in this study. It

is not accidental that, while most participants of the first group, those renouncing their distressing experiences, were recruited from follow-up services of inpatient psychiatric units, all participants of the group in question were recruited from community mental health services and self-help organizations. In terms of demographic characteristics, most participants in this group would be defined as having a working class background, and only some a middle class background, as opposed to participants in the first group, who have all working class background. They were all born and brought up in urban environments, while some participants from the first group were raised in rural areas. They have all completed secondary education and most are further and higher education graduates, a finding which is characteristic across groups.

Participants have a broad age range, from 23 to 49 years, having been born in the 1970s, 1980s and 1990s respectively, an age range also shared between groups. However, most participants in this group experienced mental distress and came into contact with the mental health service system after 2000, a period which in Greece is characterized by the development of community mental health care (Christodoulou, Ploumpidis, Christodoulou, & Anagnostopoulos, 2012). Participants describe a range of unusual and distressing experiences, such as unusual beliefs, hearing voices, strange bodily sensations, an altered sense of reality, as well as a range of dissociative and withdrawal reactions. They have all received various diagnoses of psychotic disorders, are on psychiatric medication, have been in contact with mental health professionals and services for several years, and most have experienced one or more psychiatric hospitalizations.

In terms of *narrative style*, a distinctive feature of participants in this group is that they produced rich narratives. Descriptions of events would be interspersed with depictions of the speaker's internal states and evaluations of the events described. In contrast to the interviews with participants located in the first group, in which it felt like the interviewer was struggling to extract information from a conversational partner who was unwilling or unable to formulate and reflect upon their life experiences, these narratives unfolded in the context of a free-flowing conversation between two competent and self-reflexive conversational partners.

In terms of *lived life story*, participants in this group as a rule made a distinction between life before and life after their breakdown, presenting the emergence of unusual and distressing experiences as a turning point in their lives, similarly to all other participants in this study. In this sense, for all narrators the emergence of severe mental health problems operates as a point of *biographical disruption*, producing a shift in their life course, which necessitates biographical reorientation, in most cases initiating a dependent biographical trajectory (Schütze, 1999). The emergence of psychosis as a point of disruption which produces discontinuity in one's life is a common theme in narratives of the experience of psychosis (Boydell, Stasiulis, Volpe, & Gladstone, 2010; Tarrier, Khan, Cater, & Picken, 2007).

Most participants tend to normalize their *life prior to the emergence of psychosis*, stressing in this way the discrepancy between a reasonably normal life before and a troubled life after their breakdown. However, in contrast to the narrations of the first group, in which difficult childhood experiences are effectively erased in a depiction of a socially prescribed

idyllic past, various negative life events and experiences come through the narratives of these participants. Participants mention various adverse childhood experiences, including troubled relations with primary caregivers, for example parental absence or neglect and discontinuity of care, adverse situations in the family of origin, such as parental conflicts and poverty, and difficult schooling experiences, such as social withdrawal, victimization or behavioural problems. Many describe a particularly troubled adolescence, characterised by conflicts with parents, behavioural problems, emotional instability, increased social isolation and substance abuse. None of the participants in this study volunteered any childhood traumatic events, in contrast to recent literature (Read et al., 2008), but most examples of childhood adversity mentioned in the literature (Bentall et al., 2014; Tienari & Wahlberg, 2008) could be discerned from participants' accounts.

Apart from two participants, who were in their 40s when they encountered the first psychotic experiences, all participants in this group started experiencing severe distress in their late teens and mostly in their early 20s, a common age for the *emergence of psychosis*. Apart from two participants, who were very quickly hospitalized amidst a psychotic crisis, most participants dealt with their distressing experiences for several years through contact with community based mental health services and professionals, even during periods of severe breakdown. Some of these participants were hospitalized in subsequent crises, when avoidance of hospitalization was no longer possible. Others were never hospitalized, despite some of them having experienced repeated psychotic crises. This is a point of distinction between the aforementioned participants, and those in the other group, for most of whom hospitalization was the first and main point of contact with the mental health service system, something that indicates the importance of *avoiding hospitalization* for effective dealing with severe mental health problems.

Another crucial distinction, however, between two groups is that participants seeking to distance themselves from their mental distress in the interview avoided recognizing their distress when it first emerged and delayed contact with mental health services, due to stigma, for long periods, resulting in severe breakdown that led to involuntary hospitalization. On the contrary, participants who in the interview acknowledge their distress, did so upon its first appearance and actively sought ways to deal with it though contact with community based mental health professionals and services. The crucial factor, therefore, appears to be not the avoidance of hospitalization per se, but rather the *timely acknowledgement and management of unusual and distressing experiences* by the persons concerned. In this sense our findings concur with the claims that delayed management of psychotic experiences is detrimental and that early detection and intervention can be beneficial (Marshall & Rathbone, 2011). It adds, however, the caveat that the type of understanding and management of psychotic experiences that individuals initially develop is crucial, and that active mobilization of the persons involved and community management of distress are essential for a favorable course. Ignoring and concealing emerging experiences of psychosis due to stigma is detrimental mainly because it makes coercive measures, such as involuntary hospitalization, which are traumatic and hinder recovery, almost inevitable in the long run.

Another difference, that emerged very clearly between the two groups of biographical narratives, concerns the role of *interpersonal relationships and social networks* in participants' lives. Participants in the first group, who renounce their experience of distress, tend to live socially isolated lives, having withdrawn to the protective bound of their family of origin, which in countries like Greece continues to play a crucial role in the survival and well-being of its members (Koutra et al., 2015), beyond which they seem to have no close relationships or engagement in social activities. What is disconcerting, though, is that this dearth of emotional ties and social engagement seems to characterize those participants' lives before the emergence of their mental health problems, as most, by their accounts, do not seem to have ever had close friends or intimate relations. Significant problems in social functioning (Addington, Penn, Woods, Addington, & Perkins, 2008) and interpersonal relations (Mondrup & Rosenbaum, 2010), as well as reduced social networks (Palumbo, Volpe, Matanov, Priebe, & Giacco, 2015) have been found to characterise individuals considered at risk of developing psychosis. These problems have been addressed in the literature in terms of 'premorbid adjustment' (Jeppesen et al., 2008) and mainly theorized as effects of individual disorder-related deficits rather than adverse familial and social environments; thus, more work is needed to understand their role in the development and course of psychotic experiences (Bebbington, 2013). On the contrary, participants in the group that is the topic of this paper seem to have always been involved in interpersonal relationships of different kinds, as well as in social activities and groups. Often these relationships are described by the narrators as disturbed and disturbing, in a few cases considered by them as being at the source of their mental health difficulties. However, what comes across as the distinctive feature of these narratives is that their narrator has been, and continues to be, living in a human and social world, as part of dynamic networks of relations, be they disrupting or supportive, with the richness of emotional experiences and social integration that these offer them. The crucial importance of intimate interpersonal relations and of engagement in social networks, that this study points to, echoes the emerging acknowledgment of the role of social support and social engagement in the literature on quality of life and recovery of persons with mental health difficulties (Anderson, Laxhman, & Priebe, 2015; Zissi, Barry, & Cochrane, 1998).

Recovery from severe distress vs recovery from the psychiatric system

Despite the shared features between participants in this group, discussed above, there are certain distinguishing features that differentiate participants in this group into two biographical types. On the one hand, there are participants who seek to make sense and manage their distressing experiences in collaboration with mental health professionals and services. In the self-help literature they would be referred to as *'users'* or *'consumers'* of mental health services (Campbell, 2013; Perkins, 2002). The 7 participants who were identified as belonging to this biographical type were recruited from community mental health services and self-help organizations. These participants produce rich descriptions of their mental distress, which they weave in the account of

their life trajectory and they relate to their life experiences. They are integrated in social and professional worlds, having intimate relationships and friends, being part of social networks, engaging in activities, some being in paid employment and raising families. They are neither distanced from nor consumed by their mental health difficulties. Instead, they come across as otherwise 'normal' people who at times struggle with bizarre, painful and uncontrollable experiences.

In their attempt to make sense of these experiences, participants in this biographical type employ variations of a biopsychosocial model, pointing to the interconnections between biological, psychological and social factors, with varying stress on one or the other, in the emergence and course of their mental distress. Correspondingly, they seek to manage these experiences through being in contact with various mental health professionals and engaging in a variety of modes of treatment, ranging from medication to psychological therapies and even participation in self-help groups. In line with the contemporary ethos of self-care (Beresford, 2002), these participants actively take on the management of their distress, through ceaselessly monitoring their mental states and navigating in the complex network of models, practices and services that characterize the contemporary mental health field.

Another distinctive biographical type is formed by participants who establish an identity through a negative dialectic with the biomedical model and psychiatric practices. These participants position themselves, some explicitly so, as *'survivors'* of mental health services (Campbell, 2013; Perkins, 2002). It is not accidental that all 5 participants identified as belonging to this biographical type were recruited from self-help organizations. These participants, similarly to those identified as users of mental health services, acknowledge and describe their experiences of mental distress. However, the emphasis in these narratives is less on making sense of distressing experiences through linking them with one's life course and more on challenging the dominant understandings and practices regarding their distress that were imposed on them. Descriptions of lack of communication with mental health professionals, ineffectiveness and adverse effects of medication and the violence of forced hospitalizations were at the centre of these narratives and were much more developed than accounts of the distressing experiences that brought participants in contact with mental health services. These narratives are much less inward looking, seeking a psychological understanding of one's state of mind. Instead, they are oriented towards recuperating a 'normal' identity from the imposition of the label of mental patient. In line with other self-identified survivors (Adame & Knudson, 2007; Cohen, 2005), these participants describe a process of recovery not so much from severe distress as from the mental health care system.

These participants also employ variations of the biopsychosocial model to explain their mental health problems. However, they do so not so much in order to provide a coherent explanation of their experience of distress but mainly in order to refute the biomedical model. Participants in this group have been, and still are, in contact with statutory mental health services, they were all hospitalized several times, some even recently, and are all on psychiatric medication. As opposed to the participants we referred to as 'users', who have faith in the mental health care system and establish collaborative relations with mental health professionals, participants who are positioned as 'survivors' start from a

position of distrust in the mental health care system, which they view as an institution of power and social control. They maintain contact with selected mental health professionals, who seem to function for them as intermediaries with the statutory mental health care system and a safety net, and who they use in order to have access to medication and to safeguard against the possibility of forced treatment. Their relationship, thus, with the mental health care system is pragmatic and utilitarian, even, we would say, manipulative.

Despite their initial and continuous contact with statutory mental health services, participants in this group sought early on alternative models, practices and professionals for the management of their distress. Crucial factors in pursuing this alternative route seemed to be their broader politicized and/or critical orientation, their increased cultural capital and support by their family and social circles in seeking alternatives. Participants describe as a turning point in their lives their encounter, often accidental, with self-help organisations, which in Greece have made their presence felt only in the last 10 years or so (Fafalios & Georgaca, 2008). Contact with and participation in these self-help organizations provided participants with the tools for a more systematic challenge to the biomedical model of mental illness, through providing alternative ways of understanding and managing distress. Moreover, it provides an identity of a 'survivor', both of distress and of psychiatry, who as a fighting subject actively manages their distress, while dismissing psychiatric practices. The adoption of the identity position of 'survivor', which operates as an axis along the lines of which one's life narrative is reconstructed, is explicit and evident in all narrations in this group. Furthermore, younger participants, through successive re-narrations of their experiences of distress in self-help groups, conferences and written testimonies, as well as through coaching others from the position of self-help group coordinators, have been 'professionalised' in this identity (Goffman, 1963), whereby the identity of 'survivor' has become the central component of their self-definition and crucial for their social recognisability.

Another crucial function for participants of engagement in self-help organizations is that it provides a collectivity and a social space, which facilitates both establishing a social network and maintaining an active organisation of everyday activities. Participants spend large parts of their time in activities of the self-help organisation, quite often through the organisation they link up with other radical collectivities, they tend to socialize with other members of the organisation and form friendships with some of them. Many of the participants had close interpersonal relationships and social networks before, which they maintain in the present, but at the same time the self-help organisation they belong to operates as a new central point of reference for their social engagement and everyday life.

Factors enabling biographical trajectories of recovery: Towards a dialectical relationship of discourses and practices

Contrary to our expectations, derived from the literature on socioeconomic determinants of psychosis (Morgan, McKenzie, & Fearon, 2008), the participants who in their narratives recognize, own and

attempt to deal with their distress do not strikingly differ from those participants who disowned the experience in terms of objective socioeconomic and demographic characteristics, such as age, gender, socioeconomic origin, place of upbringing and educational attainment, which implies that no single factor is crucial in shaping a person's life trajectory with regard to their psychotic experiences. This oriented our analysis towards mapping the complex networks of factors that combine in leading people with severe distress to differentiated life trajectories. In what follows we will attempt to examine the intersection of structures and practices in the formation of these biographical trajectories, with specific reference to the relationship between on the one hand professional institutions, knowledges and practices and on the other social networks and popular discourses on mental health as determining factors of a person's biographical trajectory with regard to severe distress.

One aspect of the lived life story of participants in this group that was distinctive concerned the existence of *interpersonal relationships* and *social networks*, both prior and after the emergence of psychotic experiences. Participants who deal with their psychotic experiences through disowning them seemed, according to their life story, to have always lived in a restricted and restrictive familial environment with limited social contact and social engagement, and they retracted even further in the protective environment of their family after the emergence of severe distress, having few, if any, interpersonal relationships and almost no engagement in social life. On the contrary, participants who recognize their experiences of distress seem to have always been part of familiar, friendship and social networks, to have engaged in activities and to have had close interpersonal relationships, which they retain to the present. We can deduce from their narratives that these participants were brought up in more open familial and social environments, which allowed them to have richer emotional and social experiences and to adopt a broader range of social roles, supported the development of their social and cognitive skills and possibly facilitated access to more progressive discourses. In this way, they have acquired the cognitive and emotional competencies and propensities to recognize and process their experiences more generally, and the distressing experiences specifically, when they were faced with them. This finding is in line with the emphasis on the role of attachment to primary caregivers, adversities in the family environment and dysfunctional family communication both in the development and in the course of psychosis (de Sousa, Varese, Sellwood, & Bentall, 2013; Gumley, Taylor, Schwannauer, & MacBeth, 2014; Tait, Birchwood, & Trower, 2004), and is also in line with the increasing acknowledgment of the importance of social and interpersonal networks and social support in the management of severe distress (Anderson, Laxhman, & Priebe, 2015; Bebbington, 2013). The parameter, however, that seems crucial in our material is the extent to which participants were raised in a socially conservative and closed family system, which restricted opportunities for partaking in interpersonal and social networks and more progressive discourses, or in a more progressive and open family system, which allowed them access to broader social networks, practices and modes of sense making.

During the last decades there has been a shift in *popular discourses* on mental health problems. As a combined result of an

increased visibility of mental distress in the media, a shift in professional discourses and practices, as well as anti-stigma campaigns, mental distress is recognized and talked about in the public realm (Pescosolido, 2013). We can assume that participants in this group, and their close environment, have access to and draw upon these public discourses, which allow them to recognize, process and publicly admit to their distressing experiences, without fear of stigmatization and rejection. On the other hand, we have seen that participants who were raised in more restrictive and conservative environments perceive their distress as a source of stigma and thus adopt a variety of strategies of distancing from it in order to avoid stigmatisation.

A crucial factor in the broadening of discourses on mental distress has been the development of *community mental health care*. In Greece the shift from asylum psychiatry to a community based mental health care system started in the 1980s (Zissi & Barry, 1997), and has been slow and disjointed, resulting in an uneven and partially developed system of community based services, which is now shrinking due the recent economic crisis (Christodoulou et al., 2012; Triliva, Fragkiadaki, & Balamoutsou, 2013). The existence of a community mental health service network provides individuals in distress who enter the system the opportunity, beyond medication and hospitalisation, to make use of available resources in order to manage their experiences. Moreover, given that access to these services is voluntary, their utilization presupposes recognition on the part of the person concerned of their experience as a mental health issue, in order to be able to seek and maintain contact with services. The community mental health care system is, therefore, predicated on and encourages individuals not only to recognize their distress, but, more crucially, to take responsibility for its management.

Beyond the range and variety of services that individuals in distress are called upon to navigate through, the development of community mental health care made broadly available more progressive discourses on mental health. These discourses permeate professional practices, which flourish in the community end of mental health services, influence the relationship between mental health professionals and recipients of their services, and thus shape the way in which individuals in distress understand and manage their experiences. At the same time, these institutional and professional discourses permeate the public domain, leading individuals who are drawn to them to seek community-based services upon the emergence of mental health problems, avoiding thus to an extent possible hospitalizations and exclusive contact with the hard end of statutory mental health service services. Thus, there seems to be a dialectical relationship between institutional and professional discourses, popular discourses and institutional and professional practices. Individuals who have access to more progressive discourses, which have partly originated from the influence of more progressive scientific and institutional discourses in the public domain, seek help in community based services which, through the management practices they cultivate, further embed these modes of understanding and managing distress.

Evidence for this can be seen in the adoption by all participants in this group of versions of the *biopsychosocial model* of mental distress, which has gained increased prominence among mental health professionals in the last few decades (Gaemi, 2009). In this model, both

individuals in distress and mental health professionals are called upon to take into account the role of biological, psychological and social processes regarding the causes, triggering and course of each person's mental health difficulties and to intervene at all levels. For psychotic disorders, pharmaceutical treatment of the biological dysfunction is deemed necessary, however individuals in distress are also encouraged to deal with the psychological and social parameters that in their case are considered as contributing to their mental health problem, for example, to change dysfunctional ways of thinking, to construct social support networks, to avoid situations that upset them, to monitor themselves for signs of relapse etc. Again, the person in distress is called upon to adopt an active stance of self-care, through monitoring and managing their mental health problems, always in collaboration with mental health professionals and services.

The assumption of agency regarding distress is also essential for the *consumer movement* in health and mental health during the last decades (Perkins, 2002; Pilgrim & Hitchman, 1999), whereby suffering subjects are considered as consumers of health services, taking on the responsibility to choose the services they will receive and to navigate within the health service system. It is also in accordance with *discourses of human rights*, which over the last decades have shifted the position of members of disadvantaged social groups from objects of protection to subjects of rights (Barnes & Shardlow, 1997; Beresford, 2002). In this frame, individuals with health, and by extension mental health, problems retain their individual and social rights, and, most crucially, interact with specialists and institutions on the basis of self-definition, retaining control over any intervention on their body and mind. Notwithstanding the very different historical trajectories, political orientations and social implications of these discourses, they all converge on positioning the suffering subject as an agent, characterized by a right to self-definition, control over and responsibility for oneself. This is the self-contained subject of late modernity, whereby the assertion of an alienable individuality of needs, desires and aspirations provides a guide for fluid subjects to navigate their way in the precarious social and interpersonal worlds they inhabit (Giddens, 1991).

The participants in this study who are positioned as individuals struggling with severe distress draw upon these discourses to assert an individuality of needs and desires, to examine and seek understanding of their mental states and to look after their mental health through collaboration with mental health professionals. These narrators are part of traditional and modern social worlds, and they seem to struggle between traditional patterns of socialization and modern demands for self-actualisation. They reflexively seek self-knowledge, that would provide them with grounding in an unstable world of relationships and norms, through flexibly adopting concepts and models of explanations that become available to them through popular and professional discourses. These explanations, however, remain at a personal psychosocial level, excluding any acknowledgment of the role of broader social and political processes, including gender politics, in the particular configuration of their self and their distress. The struggle between traditional and modern social worlds as well as the inward looking orientation of these participants are crucial elements of femininity, at least in contemporary Greece (Loizos & Papataxiarhes, 1991), and it is

not surprising that all but one of the participants in this biographical type are women. The examination of the role of gender as a differentiating factor in the biographical trajectories of people in severe distress is something we plan on discussing in a different paper.

Participants who position themselves as survivors of severe distress and of psychiatry also draw upon the discourses outlined above, but the assertion of their individuality takes a more politicized form of forging an identity through rejecting the biomedical model of mental illness and resisting the psychiatric practices that derive from it (see also Adame & Knudson, 2007; Cohen, 2005). Many participants in this group indicate that they had a politicized and critical stance from very early on, however for all of them the crucial turning point was their encounter with self-help organizations and the discourses that these made available to them. Critiques of dominant models and practices regarding mental distress flourished from the 1970s onwards with the development of the anti-psychiatry movement and the user movement, and both movements have grown and mutated to different forms in the following decades (Campbell, 1996). Notwithstanding the differences between the two movements, as well as internal differences within each one, their contributions in the last decades can be summed up to a sustained critique of psychiatry as an agent of social control, the development of non-pathologising models for understanding mental distress, and most importantly, the development of alternative strategies for managing distress. Moreover, self-help organizations function as alternative communities, in which their members can rebuild their social network and everyday life, as well as forge a socially recognisable identity. In Greece, although anti-psychiatry had some impact in the 1970s, the self-help movement did not really make its presence felt until the early 2000s (Fafalios & Georgaca, 2008). Participants who consider themselves as survivors experienced this shift relatively recently, when they accidentally came across some self-help organisation. However, this has been crucial for re-orienting the understanding and management of their distress, as well as for adopting a new identity. In terms of gender politics, the emphasis on ideological critique and the establishment of a positive fighting identity, while avoiding any reflexive psychological exploration, is characteristic of masculinity, and more so of the unreconstructed traditional contemporary masculinity in Greece (Loizos & Papataxiarhes, 1991). It comes as no surprise, then, that all but one of these participants are men.

In conclusion, this analysis highlights the dialectical relationship, at the level of discourses, between the scientific discourse of the biopsychosocial model of mental distress and the institutional discourses of mental health consumerism and patient rights, which, through their dissemination in the public domain contributed to the formation of more progressive popular discourses, which enable the recognition and communication of mental health problems by those who experience them. At the level of practices, the availability of various services and practices for managing distress through the community mental health service system provided the possibility to people who, due to resources acquired from their upbringing, had access to these discourses and practices to adopt a position of agency with regard to their distress and actively assume its management. In line with discourses of gender, women tend to assume a position of individual responsibility through

struggling to make sense and manage their personal suffering with the aid of professional systems of knowledge and in collaboration with professionals. Men, on the other hand, tend to forge a new identity of an active agent who is opposed to the dominant systems of knowledge and practice, through recourse to the discourses, practices and communities afforded by the self-help movement.

In terms of socioeconomic determinants of the development and course of psychosis, we arrive at a complex picture, which involves a dialectical relationship between structures and practices in the mental health field and beyond. Familial, social and institutional discourses and practices interact in complex ways to determine individual biographical trajectories marked by experiences of severe distress. However, even the most favorable biographical trajectories, which exemplify the processes of recovery from severe distress, tend to confine the recovery process to an individual journey of personal development. The participants positioned as users exemplify the agentic self-reflexive subject of late modernity taking on the task of the care of the self. The participants positioned as survivors articulated a critique of the biomedical model and psychiatric practices and also engaged with the alternative empowering discourses and practices of the user movement. They also, however, fell short of recognizing the social and material context of theirs and others' distress and thus of orienting towards collective action for social change. This, we would argue, would require practices of 'conscientization' (Montero & Sonn, 2009), which are still to be developed in the field of mental health and even more so to the experiences of severe distress (Harper, 2016).

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