

Socially differentiated life trajectories towards and through psychosis: A biographical study

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(long version)

In this talk I will present a study looking at the effect of socioeconomic inequalities on the development of psychosis and on life with it. This study is currently underway and we are mid-way through the analysis. For this reason I will present the methodological design and process of conducting the study, and I will mention some preliminary findings, that emerge from our first impressions and overview of the data.

The aim of the study was to examine the role of social factors in the biographical trajectory of people towards the manifestation of psychotic phenomena as well as their therapeutic trajectory in the period following the emergence of psychosis. On the basis of the relevant literature, it was expected that the trajectories towards and through psychosis would be differentiated on the basis of the person's position in social stratification and their class origin.

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, that the use of the term 'psychosis' as a more progressive alternative is not without its problems.

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Literature review and rationale

The role of socioeconomic factors in the development of mental disorders has been extensively documented in the relevant literature. It has been shown how several factors implicated in mental health, such as socioeconomic status, profession, education, social capital, life events, chronic adversity, urban living etc., interact in ways that cumulatively affect mental health with regard to common mental disorders. However, the studies examining the interaction of social parameters in the course towards psychosis are significantly less.

In the **sociology of mental health** literature the social factors have been examined mainly as objective conditions that affect mental health, through quantitative studies which evaluate these conditions and attempt to statistically correlate them to mental health indicators. This approach has highlighted the mediating mechanisms and processes, for example forms of socialization, access to resources, social support etc, through which objective socioeconomic indicators affect mental health. The present study attempts to examine further the mechanisms and processes through which socioeconomic inequalities adversely affect mental health by highlighting the breadth and complexity of these parameters, the way they are actualized in individual biographies as well as their importance for people's biographical trajectories.

The sociology of mental health has also examined the way in which objective social conditions interact with the subjective position and action of social subjects, that is to say, the relation between social structural factors and personal understandings and strategies of acting subjects. The present study attempted to expand this field by studying how these processes are actualized in the micro-level of the biographical trajectory of people with psychotic experiences. The present study aims to examine: (a) the complex processes through which objective social indicators influence people's biographical trajectory and mental health, (b) the interaction between social factors and the interpretations and strategies of acting subjects, and (c) the way people themselves perceive the role of social factors in their personal trajectory and their interpretations regarding their life course and their mental health problems.

In sum, the present study is based on existing literature regarding the role of social factors in mental health and attempts to utilize it and extend it through highlighting (a) the complexity of these processes, (b) their actualization in individual biographies, and (c) their perception and interpretation by acting subjects.

There is also extensive literature on the **lived experience of psychosis**, which examines the ways in which people themselves experience psychosis, as well as people's interpretations and views regarding

their mental health problems and their effects on their lives. This literature utilizes qualitative research methods and so firstly examines the complexity of these phenomena and secondly highlights the perspective of persons with experience of psychosis. This body of literature has, however, two limitations, which the present study attempts to overcome. Firstly, it relies on the experience and views of participants and thus focuses on psychological processes, sidestepping the role of social factors. Secondly, the vast majority are synchronic studies examining experiences and views in the present, and thus do not provide information on the participants' diachronic trajectory and the biographical factors that have shaped it. The present study (a) places emphasis on examining the role of social factors in mental health, and (b) retrospectively studies the diachronic biographical trajectory towards psychosis and within it.

The study examines **two phases** of the biographical trajectory of people with experience of psychosis:

- (a) The first phase concerns the **biographical trajectory up to the emergence of psychosis**. This phase covers experiences and life events from early childhood to the first years of adulthood, when psychotic experiences most commonly appear. The aim is to examine the experiences, events, relationships, interpretations and strategies of the person in each phase of their biographical trajectory, and to trace both how they interact in each phase and how they are sequentially organised. It is expected, on the basis of the relevant literature, that people's biographical trajectory will be differentiated depending on the person's position in social stratification and that the analysis will culminate in differentiated patterns of biographical trajectories towards psychosis along the lines of participants' socioeconomic background.
- (b) The second phase concerns the period of a number of years 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 perception by the experiencing subject, 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. Here it is also expected that the persons' therapeutic itineraries and the effects of psychotic experiences on their lives will be differentiated along the axis of their socioeconomic positions, and that the end result of the analysis will be distinct, socially differentiated trajectories within psychosis.

On the basis of the literature, we came up with **two diagrams**, one for each phase, which served as a **conceptual guide** both (a) for the questions asked and areas explored during the interviews and (b) for the analysis of the interview material.

The biographical approach

The study methodologically adopted the research paradigm of the **biographical approach**. The biographical approach draws upon the hermeneutic qualitative tradition and examines the way in which acting subjects perceive and interpret aspects of their personal biography. The biographical approach attempts to combine the personal and the social, and its particular focus is the historically formed and socially and materially constituted subjectivity. The biographical approach examines 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. Moreover, a founding assumption is that the ways in which subjects perceive their life trajectory and their present situation are biographically shaped, in the sense that each acting subject crystallizes, always on the basis of socially available resources, in the course of their life a biographical narrative, which serves as a guide for making sense of the past and present and guides action in the social field.

The biographical narration is a complex and multi-layered text, which expresses several processes and can thus 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. It also provides information on the **lived life story**, that is to say, the ways in which the subject experienced, understood and consequently acted in the specific contexts of their life course. In our case, through the interviews we can trace the conditions and events that are linked to the emergence of psychosis and the subsequent processes of its management.
- It 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. In our case, we can see how from the perspective of the present participants understand the factors that led them to experiencing psychosis, as well as the experience of psychosis and the way they have managed it.
- It refers to the **socially available resources**, from which the narrator draws and through which the biographical narration has been formed, such as traditions, shared attitudes, collective representations and discourses. We can thus trace the way in which socially available resources have shaped participants' life course and biography with regard to the experience of psychosis.
- 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. Through the biographical narration we can trace how the speakers' subjectivity is constituted, both at the level of their narrated life course and at the level of the present of the narrating act.

- It refers to the **interactional context** within which the biographical narration is produced, since the immediate context influences its constitution. We therefore take into account the ways on which the interactional context of the biographical interviews affects the content and form of the narrative.

Collection of research material

We conducted thus **30 biographical interviews** with people with psychotic experiences.

Because we wanted to capture how people manage psychotic experiences in the first few years from their emergence, uncontaminated by possible chronicity and institutionalisation effects, we specifically interviewed people who **experienced their first psychotic episode 5-10 years ago**. We also wanted to talk to people who considered themselves in recovery or recovered from psychosis, and since this usually takes time, for these particular participants we did not maintain a time limit from the first psychotic experience.

We also wanted to ensure a maximum **internal differentiation of the sample**, both in terms of participants' socioeconomic position and in terms of their therapeutic itineraries. For this purpose we selected several sources for participant recruitment. More specifically:

- Public in-patient mental health units – we recruited participants from acute and follow-up units of a mental health hospital in Thessaloniki (11)
- Public community services – we recruited participants from a mental health center of a regional town (5)
- Self-help organizations – we recruited participants from advocacy organizations, self-help groups and parents' associations in Thessaloniki and Athens (10)
- Psychiatrists in private practice in Thessaloniki (4)

In all cases one **biographical interview** was conducted with each participant, by Anastasia Zissi or myself. Of course all ethical principles were adhered to both in the process of recruitment and during interviewing participants. The interviews lasted from 30' to almost 120', depending on the participant's capacity and willingness to elaborate on their life. The interviews started with a request to the

participants to recount their life in chronological order, and the interviewers were subsequently guiding the course of the narration with questions concerning specific aspects of the participants' lives, according to the diagrams presented earlier.

The interviews were highly varied between them, in terms of their formal properties, the richness of narrative detail, the life courses described, the subjectivity constructed by the narrators. It is obvious that there is no one kind of life trajectory towards and within psychosis. The question of whether and how the diversity of the material collected can be clustered in distinct patterns is what we are currently investigating through the analysis of the material.

Processes of analysis

There is no one way of analyzing biographical material. As I indicated above, there are several layers at which a biographical text can be analysed, which are of course interrelated, but each study, depending on the research questions, can focus on some rather than others. Some biographical studies, for example, focus on reconstructing the participants' life course in order to depict historical events and processes. Others focus on the processes through which participants construct their biography from the perspective of the present and the effects this has for their current subjectivity. Each layer requires different analytical tools and usually a combination is used.

We started with a detailed **micro-analysis** of some interviews, which examined both the form and context of the text and which looked at all layers simultaneously. More specifically, the axes of analysis were:

- narrative style
- form of language use
- relationships and social environment narrated
- life events narrated
- participants' position with regard to their mental health problem
- participants' position with regard to treatments offered
- subjective positioning with regard to psychotic experiences
- positioning with regard to the interviewer

After analyzing the first 5 interviews, we realized that, although this was very useful and generated a vast wealth of analytical material, it was too elaborate to be used as the initial analytical strategy. Extremely long texts of analysis were generated for each interview, which took a very long time to produce. The

main issue, however, was that we were getting overwhelmed and unable to prioritize the most important issues that needed examining in more detail. We decided that a better strategy would be to find ways to organize our material along certain analytical axes, in order to have a more concise map of it. The micro-analysis would be the final step and could be applied either to selected interviews or selected extracts in order to answer more specific questions that have risen out of the organisation of the material.

We decided on two strategies for organizing our material, which we are currently implementing:

- Creating broad **clusters of biographical narratives** on the basis of specific characteristics of both form and content
- Composing a **chronological table** for each interview, containing a thematic summary of the participant's life course, so that we can have a schematic picture of each participant's life course and therapeutic itinerary

From these two strategies we expect to deduce certain patterns, which can then be correlated between them and with social parameters in order to arrive at broader, theoretically informed conclusions.

Preliminary results and thoughts for further investigation

A preliminary theoretical distinction, which guided our sampling strategy, was that between a person's **traditional vs. alternative orientation** with regard to their understanding of their experience and choice of therapeutic itinerary. From a first overview of our results, we maintain that this distinction is valid, and is a central differentiating criterion of our sample, but a reformulation of the terms 'traditional' and 'alternative' was required. The participants who we would classify now as having a traditional orientation are those who exclusively adopt a medical/biological interpretation of their experiences and manage them exclusively with medication. The term 'alternative' orientation refers to those participants who had the opportunity to process their experiences beyond the biomedical model. Many participants seem to assume authorship of their experience, to have thought about it and to play an active role in managing their relation with mental health services. However, most commonly these participants also adopt a biological view of their experiences as symptoms of a disease. In this sense, the term 'alternative orientation' does not refer to an exclusively non-medical understanding of psychotic experiences or recourse to non-medical ways of managing them, something that was encountered only in a small minority of participants.

On the basis of this distinction, our sample seems to be organized in 4 broad **clusters**:

- **Patients** – This applies to all participants drawn from in-patient units and some from community mental health services, who adopt a medical understanding of their mental health problem and who position themselves as patients in medical discourse, that is to say, as objects or passive recipients of expert medical care.
- **'Incidental' patients** – This includes a few of the participants from inpatient psychiatric units. These participants do not recognize any mental health problem or psychotic experience, do not attempt any interpretation of such experiences and present their contact with mental health services as incidental. This is not the result of rejecting the medical model of distress, as participants in the cluster of 'survivors' do, but seems to indicate denial or distancing from any psychotic experience and the identity of a mental health patient that this entails.
- **Users/Consumers** of mental health services – This applies to the majority of participants from self-help organizations and some participants from community mental health services. These participants understand their mental health problem as a combination of biological and environmental factors and actively assume its management through systematic contact with mental health services and professionals.
- **Survivors** – This applies to a small number of participants, drawn from self-help organizations, who reject the medical model, adopt a critical stance with regard to mental health professionals and services and seek alternative ways of managing their experience

The positions of patient, user/consumer and survivor, as subject positions and perspectives of constitution of experience and discourse, have long been recognized in international literature, and this is where we drew them from. The positions of patient and survivor are also known in the Greek context for a few decades. The position of service user, although common in Anglosaxon literature due to the emergence of the consumer model in the organization to services since the 1970s, is new to the Greek context, where mental health services are not organized along consumerist lines. However, judging from the percentage of participants adopting this position, it seems to be growing fast amongst people with mental health problems who are in contact with community mental health services and self-help organizations.

In terms of the overall quality and style of the biographical narratives produced, we could draw a broad distinction between **two kinds of narratives**:

- The participants taking up the position of 'patients' and 'incidental patients' tended to produce quite **impoverished narratives**. These were short, quite often precise and descriptive, but lacking

in detail and elaboration. They usually took a question-answer format, whereby the participant responded to the interviewer's questions by providing the information requested, but there was no free-flowing narrative. There were usually references to events and situations but very little introspection. Generally the lack of references to internal states as well as the lack of explanation and evaluation produced a very factual, descriptive, almost bullet-point type of narrative, with no sense of a thinking, reflective narrator.

- On the other hand the participants taking up the position of 'users' and 'survivors' produced **rich narratives**, full of detail. Descriptions of events would be interspersed with depictions of the speaker's internal states, both at the time of the events narrated and in the present of the interview, and with evaluations of the events described and their effects. The narrative followed a chronological order and was flowing freely, with minimal probes by the interviewer.

These quite distinct types of narrative were also identifiable in terms of the impact they had on the **interviewer**. In the first it felt like the interviewer was struggling to extract information from a conversational partner who was unwilling or unable to reflect upon and formulate their experiences beyond a dry factual description. The second type of narrative unfolded in the context of a free-flowing conversation, whereby the interviewer initially set the scene and subsequently accompanied the narrator in their journey of self-disclosure with comments, requests for further elaboration, even self-disclosure.

It would be tempting to assume that the poverty or richness of narrative reflects the narrator's internal world, as many narrative researchers do. However, we are fully aware of the complex interrelation between speech and the speaker, as well as of the role of context in the type of speech produced. Our starting premise is that the poverty of narrative does not necessarily indicate **inability** on the part of the speaker, but could also indicate **unwillingness** on their part to volunteer crucial information about their life. We might even hypothesize that for some participants it is the case of unwillingness not only to express but also to reflect on the course of their life, due to frustration and stigma. On the other hand, if we assume that the poverty of narratives is due to the speakers' inability to articulate a complex narrative about their lives, this could be due to the participants' difficulties in thinking and reflecting, but also to the effects of their systematic contact with the psychiatric establishment, which discourages reflection, and/or to the numbing effects of the high doses of psychotropic medication these participants are on.

In terms of their **social class background**, almost all of the participants recruited from in-patient psychiatric units were of working class background, something which confirmed our expectation, which is based on relevant literature, that individuals on the low end of the socioeconomic hierarchy receive the hard-end of public mental health services. The same concentration of participants from low socioeconomic status was found amongst those recruited from community mental health services. The group of participants drawn from self-help organizations was spread from low to middle class background, despite our expectations that in the more alternative end of the spectrum we would encounter primarily individuals from middle class backgrounds.

One noteworthy element is that the vast majority of our participants come from working class backgrounds. It is also worth noting that the position participants adopted and the richness of their narrative did not correlate with their class background but rather with the kinds of services they were recruited from. Working class participants interviewed in the context of inpatient psychiatric units adopted the position of 'patients' and 'incidental patients' with the corresponding poor narrative, while working class participants interviewed in the context of a mental health center or a self-help organization positioned themselves primarily as 'users' and produced a rich narrative of their lives.

The first tentative conclusion we can deduce from this is that **class background per se does not determine a person's course with regard to understanding and management of their psychotic experiences**. If we are to pinpoint the parameters that drive people with psychotic experiences to different orientations with regard to their experience and different therapeutic itineraries, we would have to look not at class background itself but to a series of mechanisms that mediate class background and people's lived experiences.

The second tentative conclusion has to do with the **role of professional practices and ideologies** in service users' orientation and management practices. It could be argued that individuals who for different reasons had a potential or a tendency to manage their psychotic experiences in a more active way tend to emerge out of the hard-end of psychiatric care and, while on occasions are still hospitalized, make more systematic use of the softer-end community-based services, which in turn foster their sense of agency and control over their experiences. This was quite obvious in the interviews conducted in Thessaloniki, a major city with a whole range of public mental health services. Almost all participants interviewed in Thessaloniki have had several hospitalizations in acute wards of the public psychiatric hospital or private psychiatric clinics, experiencing thus the hard-end of psychiatric treatment. Some have remained captive of this system, attending the follow-up service of the psychiatric hospital between hospitalizations, where they are monitored and prescribed heavy dosages of medication. These

are the participants positioned as 'patients' and 'incidental patients' in the interviews, who clearly have not developed a way of reflecting upon, understanding and managing their experience and are only passive recipients of medical care. Other participants are in contact with specific psychiatrists in community or out-patient mental health facilities, who they utilize for monitoring their situation. Here it could be argued that, in cases where options exist, the individuals with more potential will end up in contact with professionals and services which will encourage and support them in adopting a more agentic position in making sense and managing their experiences. This also highlights the importance of the existence and availability of such professionals and services, as well as their crucial role in shaping people's understanding and management practices. It is worth noting the situation regarding participants recruited from a regional mental health centre located in a town, where the only public mental health facilities are a mental health centre and a psychiatric unit in the general hospital. Staff from both services have received training on the Open Dialogue model and as a result they have developed a network whereby individuals with a diagnosis of psychosis, especially first episode cases, are followed after hospitalization by the psychologist of the psychiatric unit and are offered systemic individual and/or family therapy at the mental health centre. Although this unique setting offered service users more opportunities to develop an agentic position than the usual network of mental health services, only 3 of 5 participants interviewed there adopted a 'user' position, while 2 adopted a 'patient' position.

In terms of **narrative content**, the **course of life** participants depicted, we have made several broad observations:

- With regard to the description of the **years of childhood and adolescence**, prior to the emergence of psychotic experiences, none of the participants mentioned any particularly traumatic life event, severe chronic adversity or experiences of neglect, abuse or violence. Some participants talked about stressful family environments, most usually due to parental conflict. A few reported experiences of discrimination, victimization and alienation at school. Very few participants mentioned having behavioural and/or emotional problems prior to the onset of psychotic experiences, usually in these cases in late adolescence. The majority of participants described a 'normal' life, possibly with some problems in the familial and school environments, but nothing out of the ordinary. This tendency to normalize life before psychosis is very pronounced in the more impoverished narratives of participants recruited from in-patient units. In these narratives, even when potentially disturbing events and situations are alluded to, they

are brushed aside as not significant, and life in childhood and adolescence is presented as more than normal, as 'perfect' and 'ideal'. This 'perfect' life seems to be a life where nothing happened, giving the impression of a life in a void.

- The **psychotic experiences** are presented as appearing out of the blue and disrupting this seemingly normal life course. Even for participants who describe behavioural and emotional problems and difficult experiences prior to the psychotic experiences, and also for those few participants who make links between prior stressful events and the emergence of their psychotic experiences, the psychotic experiences are described as qualitatively different and as **constituting a break** from their previous experiences. All participants describe the beginning of their psychotic experiences as **something that happened to them**, as something foreign, inexplicable and uncontrollable. There is marked **difference in the way the psychotic experiences are talked about** between the two kinds of narratives mentioned above. In the impoverished narratives, produced by participants at the hard-end of the psychiatric establishment, there is no reference to actual experiences. The participants seem unable or unwilling to reflect upon and describe thoughts, feelings, perceptions and sensations, even as a response to questions by the interviewer. What has happened to them is referred to with terms such as 'and then I got ill', 'and then I got schizophrenia', as an illness that they suffer from, which is devoid of meaning. On the contrary, in the rich narratives, produced by participants attending community mental health services and self-help organizations, the psychotic experiences are described in detail. They are still presented as something foreign and uncontrollable, but they are owned by the person as experiences they had, and sometime still have, that they can reflect upon and talk about.
- After the start of experiencing psychosis, almost all participants were hospitalized, and most had experienced repeated **hospitalisations**, in public and private psychiatric clinics. The act of hospitalization, most usually involuntary and initiated by the participants' families, does not seem to be directly related to the acuteness of the psychotic crisis, as to the concerns, worries and attitudes of the family. This was obvious to us, as we have heard in interviews accounts of very severe and prolonged psychotic crises, which were dealt with at home with the mobilisation of the family, and on the other hand, accounts where the family initiated compulsory hospitalization procedures on the basis of minor psychotic experiences. In all cases hospitalization was described as a traumatic experience. There were variable evaluations between different private and public clinics, but all participants described experiences of feeling

violated, of fear and helplessness, as they were forcibly injected with medication and mechanically restrained, both of which are common practices in Greek inpatient psychiatric facilities. It is our first impression, which is of course in need of analytical examination through the data, that managing to delay or avoid hospitalization plays a significant role in participants' possibilities to manage better their experiences and potentially recover.

- In terms of **therapeutic itineraries**, before or between hospitalizations, there seems to be variability, whereby most participants have tried various options and visited various mental health professionals and services. Participants may have their medication monitored by psychiatrists in private practice, in public health centers and/or in outpatient and follow up public psychiatric units. In some cases they have been offered supportive counselling and/or psychotherapy by psychiatrists and psychologists in private practice and mental health centres. Some participants, especially those at the hard-end of the psychiatric system, seem to be stuck in an invariable contact with the follow up unit of the psychiatric hospital, where they only get their medication monitored between hospitalizations. Most other participants have tried various courses of action before settling into their current pattern of mental health care. Many recount several unpleasant and unsuccessful experiences with mental health professionals, mainly psychiatrists, which they subsequently sought to replace with professionals and patterns of care that are more helpful and workable for them. There seems to be a pattern of participants going through periods of being stuck in the mental health care system until eventually figuring out ways of utilizing it for their benefit. In any case, what becomes apparent is that most participants take an active role in shaping their mental health care, always of course within the constraints of the options available and offered to them. Moreover, it seems that the more active people are and the more helpful mental health care arrangement they get into, the better they fare in terms of managing their situation.
- Experiencing psychosis, paired up with subsequent hospitalizations, heavy dosages of medication and social stigma, has **debilitating effects on people's lives**, affecting the major roles of adulthood in terms of love/marriage and work. Some participants seem to have had intimate relationships prior to the first psychotic experiences. Others seem to always have had difficulties in this domain or the psychosis came too early, before they had a chance to experience a sexual relationship. The vast majority of participants has not continued with these relationships and/or has not managed to have intimate relationships since. A similar pattern can be detected with regard to work, whereby the onset of psychotic experiences either disturbed a starting work

trajectory or precluded the possibility of establishing work from that point on. Again the vast majority of participants have not worked since the beginning of their mental health troubles, although most strongly wish they do. The prospects of creating a family and having children, although desirable, looks like a distant dream for most. Most participants report few friendships before the onset of psychotic experiences, and even less in the present, something which indicates the lack of a supportive social network. Some participants received disability benefits and others not. In any case, given the dire amount of disability benefit and the increasing obstacles in securing it, most participants are dependent on their family for financial support. More generally, participants seem to have withdrawn back into their family of origin, which provides the means for subsistence, accommodation, emotional support and a refuge from the social stigma and rejection they face from the outside world. Participants talk dearly about the comfort and security they experience within their family, although they also talk about the strains of this coexistence with their parents. There is a prevailing sense in the interviews of people's frustration for having lost, for some irretrievably, major adult roles, as well as for continuously facing stigma and rejection. To this most participants respond with resignation and withdrawal to a safe and eventless life within the confines of their family of origin. Most speak of plans for intimate relationships, creating a family and finding work. A few only, though, have made active steps in this direction, in a way that these seem to be realizable prospects.

- When asked **what helps them manage these experiences**, participants who are actively coping list various sources of support, including medication, their contact with mental health professionals and services, getting support from their immediate family, intimate partners and friends, and finally entering supportive communities, such as self-help organizations and radical collectivities.

Participants manage their **subjective positioning and identity with regard to their psychotic experiences** in various ways.

- The participants who position themselves as 'patients', who understand their experiences as symptoms of an illness that they suffer from, and which moreover carries significant social stigma, adopt different strategies to distance their identity from their psychotic experiences. Firstly, they refuse to describe the experiences related to their mental health troubles, that is to say, to talk about what they feel, think or perceive, and therefore do not assume ownership of these experiences. They talk about it as an illness that they suffer from, distancing thus the

illness from their self, and presenting it as something almost external that imposes upon the self and affects it, without being part of it. Sometimes, they circumscribe the illness in time, so that it appears as a parenthesis in an otherwise continuous life course and identity.

- At the extreme end, participants positioned as 'incidental patients' completely deny ever having had any such experiences and being mentally ill, despite referring to their taking medication and continuous contact with mental health services.
- The participants positioned as 'users' of mental health services describe their psychotic experiences as experiences, that is to say, as subjective states, and thus assume ownership of them. In some cases these experiences are described as imposed and foreign, in other cases they are linked to the participant's life and other internal states, such as needs and attitudes. These participants present themselves as people who occasionally have strange, unusual and distressing experiences. Most consider these to be the effect of an illness they suffer from, while others also give psychological and social explanations. In any case, the psychotic experiences are subjectivised, constructed as parts of participants' identity. Their likely persistence is in most cases recognized and participants are determined to continue taking measures to manage them as best they can. The identity these participants assume is akin to that of a person with a chronic debilitating condition, which requires continuous vigilance and monitoring, looking after oneself as an act of prevention and active managing in times of crisis.
- The few participants positioned as 'survivors' share all the features mentioned above with regard to the 'users' of services, in terms of ownership of the experience, viewing it as an aspect of their self and identity and active continuous managing. However, while the 'users' group treat these experiences effectively as a chronic illness and are therefore open to a medical explanation, 'survivors' reject any medical view of their situation and adopt exclusively psychosocial models of understanding what has happened to them and what they experience.

There is also a pronounced difference between the groups of participants with regard to their **attitude with regard to mental health services**.

- Participants positioned as 'patients' assume a passive role in relation to their condition and are subjected to the views and practices of medical experts. They usually list the medications they take, without being able to discuss what these medications do and how they affect them. They do not seem to have considered whether the specific services they attend or the specific care

regime they are under are helpful to them or to have sought alternatives. The same applies to participants positioned as 'incidental patients'.

- Participants positioned as 'users' consider themselves as suffering from a chronic condition and are therefore oriented to the medical establishment for its management. They adopt active self-managing strategies but they also rely on expert knowledge and advice, which they seek and utilize. They are not passively subjected to mental health professionals' judgments and practices, as they assume an active role in finding out about their condition and treatment options and seeking the forms of care that suit them best. We would say that these participants defer to and rely upon expert knowledge and practice, but at the same time they utilize it, forming partnerships with mental health professionals for the benefit of their mental health. This is consistent with the consumer movement in services and with the neoliberal autonomous subject, who takes responsibility for their wellbeing, always in accordance with expert knowledge.
- Participants positioned as 'survivors' also have this utilitarian view of mental health professionals and services. They explicitly use them as a source of provision and support, in order to ensure that they get what they consider the best possible mental health care. 'Survivors', though, differ from 'users' in that they start from a position of distrust of expert opinion and of refusing to defer to an assumed position of expertise in the first place. Stories of mental health professional arrogance, damaging treatments and abuse in the hands of mental health services abound in their narratives. Participants positioned as 'survivors' consider that mental health professionals do not know what is best for them and that the mental health system has harmed them. On the other hand they know they have to retain a certain contact with it, both in order to avoid compulsory hospitalizations and treatments and in order to secure medication and other forms of mental health care provision they consider helpful. More than a partnership, they form thus strategic alliances with mental health professionals and services, quite often based on selective volunteering of information and deceit, especially when it comes to strategies of reducing medication.