

Chapter 2

Eppur si mouve



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2.1 When Empiricism Faced the Challenge of Psychosis

In the 1950s, the introduction of neuroleptics, along with the discovery of chlorpromazine (synthesised by Charpentier, who was looking for an antimalarial compound and suggested to psychiatry by Laborit for its sedative properties and finally brought to the field of psychiatry, led to a new approach, and finally brought to the field of psychosis by Delay and Deniker), entailed a revolution in the treatment of psychosis that facilitated the deinstitutionalisation of the mentally ill patients, and with it the psychiatric reform, which has progressively spread globally.

Shorter (1997) noted that “chlorpromazine started a revolution in psychiatry, comparable to the introduction of penicillin in general medicine”. The first neuroleptics were followed by numerous important empirical findings that pointed out the causality of psychosis in the functioning of the brain neurotransmitter systems. New generations of increasingly selective pharmacological molecules emerged, which seemed to presage that “Science” would be able to control “madness” once and for all.

However, more than 70 years have passed and the enormous expectations placed on antipsychotic drugs have not been fully fulfilled. In this regard, Thomas Insel

Eppursimouve (“and yet it moves”), a phrase attributed by Giuseppe Baretti to Galileo Galilei.

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(former president of the National Institute of Mental Health, NIMH) stated that “the long-term outcomes for people with “schizophrenia” remind us that 100 years after defining this disorder and 50 years after “breakthrough” medications, we still have much to learn” (Insel, 2013).

An increasing number of studies explicitly state the limitations of pharmacological treatment. Whitaker (2005) notes that since the introduction of chlorpromazine in the United States, the percentage of people with disabilities caused by mental disorders has increased fivefold, raising the question: Have we made any progress in the treatment of patients with severe mental illness?

Already in 1967, NIMH researchers found that at the one-year follow-up “patients who received placebo treatment in the drug study were less likely to be rehospitalised than those who received any of the three active phenothiazines” (Schooler et al., 1967). Three other studies (Carpenter et al., 1977; Rappaport et al., 1978; Mosher & Menn, 1978) were funded by the NIMH in an attempt to clarify this question. Their conclusion was disconcerting: the treatment with neuroleptics could increase the incidence of long-term relapse.

In the same vein, more recent studies (Kishimoto et al., 2014; Lepping et al., 2011; Stone et al., 2018; Leucht et al., 2009) demonstrate better long-term outcomes in those who did not receive neuroleptic medication or discontinued its use. These results seem to be related to other studies that link the long-term use of neuroleptic medication with impairment (Pillinger et al., 2020; Husa et al., 2014; Ibi et al., 2017; Pol, 2015; Furukawa et al., 2015; Lieberman et al., 2005), or with better functioning after its discontinuation (Albert et al., 2019), or even with negative symptomatology (Artaloytia et al., 2006).

This is in line with the model presented by the British psychiatrist Joanna Moncrieff in her work “A straight talking introduction to psychiatric drugs” (2013) where she postulates that taking psychiatric drugs merely serves to replace the original mental state of the problem with the drug-induced mental state; in other words, taking a drug does not bring an organism from an abnormal functioning system to a normal one, as an illness-centred model assumes; on the contrary, it keeps the organism in an abnormal and biologically stressed state.

The main empirical theories about the (organic) cause of psychosis and the mechanisms of drugs in psychosis have also been strongly questioned. A recent meta-analysis rejects the dopaminergic and glutamatergic hypotheses as to the origin of psychosis (McCutcheon et al., 2021), which would leave the pharmacological explanation and approach to psychosis without an “efficient cause”. Other studies report that there is no discernible difference in effectiveness between first- and second-generation antipsychotics, as well as negative effects associated with both (Saucedo-Uribe et al., 2020; Stone et al., 2018; Leucht et al., 2009). Or that, at best, their efficacy has been overestimated (Morrison et al., 2012).

With all of this and in line with Whitaker (2008), “the evidence calls for selective, cautious use of the drugs...” because, while the benefit of medication in reducing distress and unwanted phenomena is undeniable, there is also evidence of a subgroup of people who have had a psychotic episode and do not require neuroleptic medication (Wils et al., 2016; Stephens, 1978). Moncrieff herself points out that,

if the disturbance is very severe, the drug-induced abnormal state may be preferred by the patient or by the people who are trying to help him or her.

2.2 Myths and Legends

Eugen Bleuler (1911/1993) built on Kraepelin's concept by coining the term schizophrenia, although he pointed out that with this term he was referring to a group that includes several diseases, the schizophrenia group. According to Bleuler, the term "dementia praecox" was inappropriate, since in many cases the deterioration either does not appear early or does not occur at all (Jablensky, 2010; Bleuler, 1911/1993). He distinguished between fundamental symptoms and accessory symptoms. The fundamental symptoms are those that are "present in all cases and in all periods of illness" (Bleuler, 1911/1993, p. 20) and, therefore, characteristic of schizophrenia, represented by the four "A's": impaired associations, disturbance of affectivity, ambivalence, and autism; Bleulerian fundamental symptoms correspond to a large extent to what we currently consider symptomatology of a negative character, while those that he called accessory symptoms correspond to the positive phenomenology. This approach emphasises the dynamic and positive character of the process, which allowed an approach to the psychodynamic perspective and thus to therapy.

Kurt Schneider's psychopathological contributions produced a turning point for the conceptualisation of schizophrenia when his work was belatedly rediscovered by anglophone psychiatry, where due to "misunderstandings or ignorance" of the author's context, definitions of the first-rank symptoms were reworked (Hoenig, 1982) and dogmatised with increasing interest, as these coincided with the positive symptomatology for which antipsychotic drugs were working. This position has been incorporated by the main diagnostic criteria manuals until their most recent versions (ICD-11 and DSM-5), since in their previous versions these positive symptoms (mainly delusions and hallucinations) were prioritised over the rest symptoms for the diagnosis of schizophrenia. However, Schneider (1997) pointed out the following:

Among the many abnormal modes of experience that occur in schizophrenia, there are some that we call first-rank symptoms, not because we consider them "fundamental disorders", but because they have a completely special weight for the diagnosis. This assessment... refers only to the diagnosis. But it says nothing about the theory of schizophrenia.... In order to establish the diagnosis of schizophrenia, it is not necessary that the first-rank symptoms are present. (pp. 170–172)

The theoretical misrepresentation reflected in the nosological manuals about the importance of positive symptomatology in schizophrenia relegated to residual consideration phenomenon such as negative symptomatology and cognitive impairment, which have been shown to be central to people's distress and lack of adaptation to their environment.

2.3 Brave New World¹

The critical and crude exposition of the alternative data that question the efficacy and adverse effects of neuroleptics has often been interpreted as an anti-psychiatric stance. Van Os and Kohne (2021) report that the commitment to a vision of schizophrenia that does not take a reductionist, brain pathology causes is often understood and labelled as “anti-psychiatry”. On the contrary, the proposal put forward is for a reconceptualisation of psychosis, beyond the consideration of it as a biologically determined deteriorating illness with the associated reductionist search for univocal explanatory biomarkers. It can be argued that this reductionist, biological framing of psychosis has had limited impact in improving care and supporting personal recovery: additionally, it may contribute culturally to maintenance of the usual clinical practice in psychosis, centred almost exclusively on the use of medication. This focus on medication (and limited consideration of other treatment approaches) may bring with it unfortunate consequences. It can reinforce a mercantilist perspective of health, promoted by the pharmaceutical industry, and maintained and reinforced by a cultural system that encourages the imperious need to obtain “fast food” happiness, as well as the possibility of resolving any discomfort by pharmacological (magical) means. This system, which may promote the avoidance of unwanted experiences at almost any cost, and therefore of life itself, also makes use of another devastating tool to mould and homogenise its consumers: the stigma.

Dainius Pūras (2017), United Nations’ (2017, 2018) Special Rapporteur on health rights, during the Human Rights Council in Geneva in 2017, stated that “...mental health systems... are based on outdated practices that violate human rights”. During that intervention, he denounced that the decision-making is in the hands of “biomedical gatekeepers” supported by the pharmaceutical industry who advocate that people with mental disorders are dangerous and that biomedical interventions are necessary in most cases, concepts that perpetuate stigma and discrimination, as well as the coercive practices that are still widely accepted in mental health systems nowadays.

Pūras advocates overcoming the over-reliance on medication and the biased use of “evidence” that “was contaminating knowledge about mental health”, encouraging a “paradigm shift to ensure compliance with the UN Convention on the Rights of Persons with Disabilities”. According to Pūras, paternalistic and over-medicalised concepts must give way to participatory, psychosocial care and support in the community. Cost-effective and inclusive options with successful outcomes exist and are being used all over the world today; they just need to be enlarged and sustained (Pūras, 2017).

¹Brave New World is the title of the novel published by the British writer Aldous Huxley in 1932. It refers to a utopian world where malaise and sadness were eliminated with the use of a single drug (soma) and without side effects.

The field of mental health professionals is also compromised, as research, scientific literature, and training are dominated with the medical-biological and pharmaco-centric perspective, promoting “mainstream psychiatry” (Pérez-Álvarez, 2021), through semiological straitjacketing and thus the conceptualisation and understanding of psychosis as a “disease”, something that in many cases prevents the development of studies and non-pharmacological therapeutic applications (despite their evidence).

“Reviews and guidelines serve to consolidate the psychopharmacological dominance and unidimensional treatments rather than to guide the implementation of much more complex (but not more costly) multi- and inter-professional systems” (Tizón, 2016, p. 22).

As Lisa Cosgrove and Emili Wheeler (2013) state

...prohibiting industry relationships is a necessary but insufficient solution; the disease model with its reductionism and de-politicised approach also must be challenged... until this epistemic shift is made, industry will continue to enjoy its colonisation of psychiatry.

Although there are comparative studies that support drug-free psychotherapy (Francey et al., 2020; Morrison et al., 2018; Bergstöm et al., 2018), the number of these is ridiculous compared to studies on the efficacy of pharmacotherapy, which is also financially supported and institutionalised. Furthermore, the comparison between psychopharmacological treatment and psychotherapy within the framework of evidence-based medicine is not adequate, given that the purpose of the interventions is not the same, since the first one seeks the reduction of the symptomatology, while psychotherapy does not have this as its ultimate goal (Pérez-Álvarez, 2014).

The psychotherapeutic approach to psychosis is not exempt from criticism. On the one hand, there is a significant shortage of qualified professionals for this type of human problem. On the other hand, the “expert perspective” can dominate the intervention, giving priority to the authority of the professional, their psychotherapeutic model, and their preconceived ideas about psychosis, instead of giving voice to the person and their experience, leaving the person invalidated and disempowered, restricting and limiting their freedom to decide, and therefore incurring epistemic injustice (Fricker, 2017).

Studies such as Stovel et al. (2016) and Wang et al. (2018) have shown how people with psychosis perceive themselves as disempowered by biomedical perspectives, having this and effect on the loss of power in their decision-making.

Other difficulties seen in the approach to psychosis are found at the structural level, such as the fragmentation of services, contradictory interests and priorities, difficulties in the funding and provision of resources, as well as the complex relationships between the administrations with social and health competences, which generate a significant lack of definition on the responsibilities, duplication of efforts, and a break in the continuity of care (Hadley et al., 1996; cited by Vallina, 2003).

2.4 The Right to Decide

In 2013, the British Psychological Society's Division of Clinical Psychology contemplated the need for a paradigm shift in relation to functional psychiatric diagnoses, advocating a multifactorial approach, which contextualises distress and behaviour, and which recognises the complexity of the interactions involved in all the human experience (Awenat et al., 2013).

From this position emerges an alternative model to traditional diagnostic systems, "The Power Threat Meaning Framework" (Johnstone & Boyle, 2018a, b). Cooke (2014) proposes as directions: a commitment to integral and team work, the replacement of paternalism with collaboration, free choice for the person to choose the treatment and to be able to express themselves freely about their experiences in a non-punitive framework, as well as an approach aimed at the prevention and working against discrimination and stigma. Recently, Valery and Prouteau (2020) pointed out that beliefs about biological causality in mental health problems constitute one of the variables most closely related to professional stigma.

Morrison et al. (2012) in their famous article "Antipsychotics: Is it time to introduce patient choice?", ask whether antipsychotics should always be the first line of choice. Van Os stated that "in the short-term antipsychotics work very well, but in the long-term people have to make their own choices", and puts the focus on "a model that increases resilience rather than suppressing symptoms and helps people to live with them" adding that "what works is the care that provides hope and where everyone works towards their life goals" (quoted in Barnés, 2018). Moreover, when people with psychosis are asked about their needs and preferences (e.g. Freeman et al., 2019), they identify challenges that are treatable with social and psychological approaches. For the types of care that meets these needs to be possible, a global change in the conceptualisation of psychosis is necessary, as well as the development of institutional and legislative policies aimed at modifying the support systems for people, working in a top-down process to dismantle and modify the current stigma, without forgetting the "bottom-up" process, such as the associative movements of people with psychotic experiences, families, and professionals who advocate for an appropriate change to the twenty-first century, such as the recently established drug-free hospital unit at the Åsgård Psychiatric Hospital in Tromsø, UNN Åsgård (Norway).

The right to decide on treatment and life course for a person with psychosis is a controversial issue. Refusal or criticism of medication has been typically seen as a lack of awareness or insight that is part of the illness itself. However, there is evidence that most people with a diagnosis of severe mental disorder are actually capable of making decisions about treatment (Cairns et al., 2005), as well as making accurate assessments of the effects of medication (Day et al., 1995), and yet they are ignored or their opinion is not given the same consideration as that of other people (Bindman et al., 2003; Szmukler, 2004).

Nevertheless, the right to decide is an area in which progressive advances are taking place, driven by non-hospitalisation focused positions and forms of

intervention and care such as: the Soteria houses initiated by Mosher (Calton et al., 2008; Mosher, 1999), the treatment adapted to needs (Alanen, 2011), or the approach in Switzerland by Emmenegger (2016), among others. See the Guidance on Community Mental Health services: Promoting person-centred and rights-based approaches, published by WHO in 2021. (Guidance on community mental health services Promoting person-centred and rights-based approaches.) (WHO, 2021).

It has been described that the use of coercive measures and physical restraint in mental health or social services is not only experienced as humiliating, but in many cases, it also produces a traumatic effect, increased by unclear and contradictory explanations about these measures, the imperative or paternalistic treatment, and the use of confusing and critical comments that do not take into consideration the emotional and cognitive situation of the person, giving rise to the experience that has been called “sanctuary trauma” (Anthony, 1993) or “welfare trauma” (Díaz-Garrido et al., 2021), especially when these services and professionals should be the guarantors of the person’s safety and care, and from them one would expect understanding, patience, and comfort.

A paradoxical effect occurs, where interventions focus on the containment of suffering and not on establishing a dialogue about the personal experience of psychosis. It is significant that the admitted patients report insufficient access to psychotherapy, which is considered a high priority for them (Jones et al., 2010; Lelliott & Quirk, 2004).

Therefore, the experience of being admitted into a psychiatric unit can be a traumatic experience with detrimental implications, in the form of longer hospital stays (Calkins & Corso, 2007; LeBel & Goldstein, 2005), difficulty in establishing therapeutic alliance and adherence to treatment (NASMHPD, 2009; Frueh et al., 2005; Robins et al., 2005), as well as the increase on the relapses and readmission (LeBel & Goldstein, 2005).

Perhaps, a non-institutional, non-medicalising, and admission-avoidance approach should be the priority; an approach that encourages a networking perspective, providing a contextual and relational understanding and getting closer to the proposal of contemporary human rights approaches (von Peter et al., 2019).

Stigma is a complex concept in which multiple effects and influences occur at different levels, which we try to represent through the following concepts: social stigma, self-stigma, and iatro-stigma (Fig. 2.1) (Díaz-Garrido et al., 2021).

Some studies suggest that an alternative system to the usual one (Open Dialogue, Soteria-Berne houses and models based on mutual support) would be effective and more economical. Following these studies, Stupak and Dobroczyński (2021) propose the possibility of reducing expenditure on medication and hospital stays, allocating these resources to better care, which would have an impact on better social and occupational functioning of these people. However, the implementation of such a system “currently seems unlikely because of the influence of parties interested in maintaining the status quo, that is to a large degree associated with the neoliberal cultural and economic order”.

From our point of view, the free decision of the individual becomes the backbone that has to guide the whole process of intervention and recovery, as well as being the

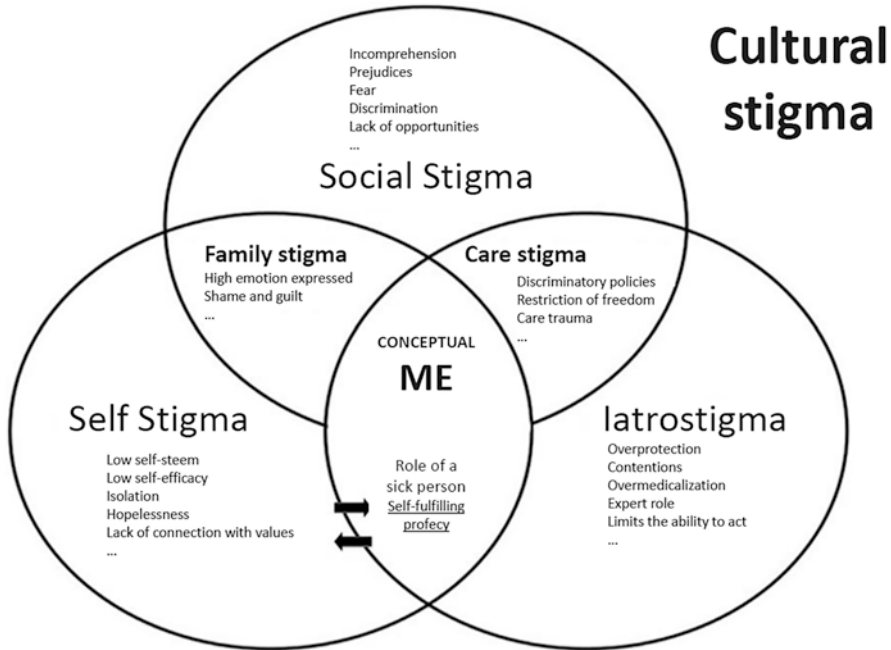


Fig. 2.1 Social stigma, self-stigma and iatrogenic stigma (Retrieved from Díaz-Garrido et al., 2021). Stigma conditions and hinders people’s free decision making. From the conceptualisation and labelling “schizophrenic”, “psychotic”, to the very understanding influenced by different factors about what psychosis is, it hinders the development of a purposeful life, with its capacity for self-development and self-fulfilment. Social prejudices deeply mark the person with psychosis and label them as “strange”, “violent”, “unpredictable”, facilitating segregation, isolation, and lack of opportunities for personal, social, and professional development. (Penn & Martin, 1998)

fundamental principle of the paradigm shift, minimising the use of punitive resources such as involuntary admission, forced treatment, and restraints; respecting the type of treatment that the person wishes to receive, be it exclusively pharmacological, psychological, or of mixed nature, knowing the risks or consequences of not adopting one or the other.

This stance would be congruent with recovery-oriented practices, for example, the CHIME model (Leamy et al., 2011): connectedness, hope, and optimism about the future, identity, meaning in life, and empowerment.

2.5 Towards a Paradigm Shift

In 2017, Thomas Insel said, “I spent 13 years at NIMH really pushing on the neuroscience and genetics of mental disorders, and when I look back on that I realise that while I think I succeeded at getting lots of really cool papers published by cool

scientists at fairly large costs –I think \$20 billion– I don't think we've moved the needle in reducing suicide, reducing hospitalisations, improving the recovery for the tens of millions of people who have mental illness” (Cited in Rogers, 2017).

Currently, a global movement is taking place from different theoretical-practical conceptions, philosophical approaches, non-governmental organisations, associations of people with psychotic experiences and family members, authors of recognised prestige, and a paradigm shift in the approach and conceptualisation of psychosis; a change that goes from the name itself (“integration disorder” in Japan, “attunement disorder” in Korea, “Salience Syndrome” or “Psychotic Spectrum Syndrome” among other proposals), to more contextualised and person-centred work orientations.

The fundamental principle of this paradigm shift is the person-centred approach and the development of transdiagnostic models, rejecting classical nosological labels. In addition, interventions linked to the person's context, the establishment of a more symmetrical therapeutic relationship, and the introduction of the person's choice are considered essential.

Many of the perspectives involved in the paradigm shift are based on principles such as: empowerment, radical acceptance, non-control, validation, etc., and therefore on changing the relationship with symptoms rather than eliminating them, which take on a new dimension in the way of understanding the approach to psychosis.

New conceptions of the severe mental disorder must take into consideration the person holistically, with his or her interests, goals, and values as the centre and direction of the treatment. They must also take into consideration that psychotic phenomena and experiences are multi-causal in nature, with strong involvement of the attachment, the trauma, and the dissociation components (Bloomfield et al., 2021).

The progress towards recovery-based treatments involves a reworking of the concept of functionality, understood as the choice of relevant and valuable directions and actions for the person experiencing psychotic phenomenology.

The paradigm shift requires the involvement of all professionals, starting from the withdrawal of the role of expert, to adopt a position of respect and trust in the person's capacity for growth, accompanying him or her and giving structure and support in the freely chosen valuable direction.

Examples of this paradigm shift are: the Power Framework, Threat and Meaning, Open Dialogue, Hearing Voices, contextual models such as Acceptance and Commitment Therapy (ACT), Leveled Acceptance and Recovery Therapy (ART), Compassion Focused Therapy (CFT), Person-Based Cognitive Therapy, Functional Analytic Therapy (FAP), Dialectical Behavioural Therapy (DBT), mindfulness-based therapies, Metacognitive Therapy, person-centred attention, the “Icarus” project, and the post-psychiatric movement, among others.

2.6 Conclusions

From the proposals for the reconceptualisation of psychosis, through the recognition of the right to the free decision of the person in the duly informed choice of treatment, the new types of treatments and approaches, to the consideration of attachment, trauma and stigma as an experience strongly associated with people with psychotic phenomena, changes are taking place in all areas related to psychosis, which seem to lead us towards a (r)evolution in the way of understanding and supporting people who live with this reality.

Although there is still a long way to go, a lot of resistance to overcome, providing discourses and arguments empirically sound to convince, we are participating in and witnessing the beginning of a paradigm shift, which, although it is in doubt, and takes some time, “and yet it moves”.

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