Social Science & Medicine 247 (2020) 112811

Contents lists available at ScienceDirect

Social Science & Medicine

journal homepage: www.elsevier.com/locate/socscimed

The collaborative management of antipsychotic medication and its obstacles: A qualitative study

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ARTICLE INFO

Keywords:
Antipsychotic medication
Collaborative management of medication
Coercion
Therapeutic alliance
Concordance
Mental health
Qualitative research
Catalonia

ABSTRACT

Antipsychotic medication is the primary treatment for psychotic conditions such as schizophrenia and schizoaffective disorders; nevertheless, its administration is not free from conflicts. Despite taking their medication regularly, 25–50% of patients report no benefits or perceive this type of treatment as an imposition. Following in the footsteps of a previous initiative in Quebec (Canada), the *Gestion Autonome de la Médication en Santé Mentale* (GAM), this article ethnographically analyses the main obstacles to the collaborative management of antipsychotics in Catalonia (Spain) as a previous step for the implementation of this initiative in the Catalan mental healthcare network. We conducted in-depth interviews with patients (38), family caregivers (18) and mental health professionals (19), as well as ten focus groups, in two public mental health services, and patients' and caregivers' associations. Data were collected between February and December 2018. We detected three main obstacles to collaboration among participants. First, different understanding of the patient's distress, either as deriving from the symptoms of the disorder (professionals) or the adverse effects of the medication (patients). Second, differences in the definition of (un)awareness of the disorder. Whereas professionals associated disorder awareness with treatment compliance, caregivers understood it as synonymous with self-care, and among patients "awareness of suffering" emerged as a comprehensive category of a set of discomforts (i.e., symptoms, adverse effects of medication, previous admissions, stigma). Third, discordant expectations regarding clinical communication that can be condensed in the differences in meaning between the Spanish words "*trato*" and "*tratamiento*", where the first denotes having a pleasant manner and agreement, and the second handling and management. We conclude that these three obstacles pave the way for coercive practices and promote patients' de-subjectivation, named here as the "total patient" effect. This study is the first GAM initiative in Europe.

1. Introduction

Antipsychotic medication is the main treatment for schizophrenia, schizoaffective disorder and other psychotic conditions that have been labelled together in DSM-V (APA, 2013) as the "schizophrenia spectrum and other psychotic disorders" (hereinafter SSPD). Nevertheless, the administration of these pharmaceuticals is not free from uncertainties. Despite taking their medication regularly, 25–50% of patients report no benefits (Lieberman et al., 2005) or perceive this type of treatment as an imposition and coercion (Verbeke et al., 2019) that leads them to medication discontinuation (between 40 and 70% of patients) (Tiihonen et al., 2017). These circumstances erode the possibility of recovery and mutual confidence between patients, mental health professionals and caregivers (Seale et al., 2006).

Since the mental health reforms of the nineteen-seventies and the subsequent creation of community-oriented services in most advanced capitalist societies, there has been a substantial improvement in the quality of life of people affected by SSPD. In contrast to the classic image of the asylum as a disciplinary institution (Goffman, 2017), community models have endeavoured to humanise psychiatric care.

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https://doi.org/10.1016/j.socscimed.2020.112811
Received 27 August 2019; Received in revised form 15 January 2020; Accepted 17 January 2020

However, it cannot be claimed that the policies and clinical practices based on discipline, control and coercion have entirely disappeared (Martínez-Hernáez, 2018). In the treatment of SSPD there are still contradictions between the ideal models of concordance, understood as "mutual respect and understanding in pursuit of an ideal therapeutic alliance" (Seale et al., 2006), and real practices. The patient's right to receive medically accurate information is recognised in many countries, but some care practices that limit participation and patients' rights continue to prevail (Rodríguez del Barrio et al., 2013). One revealing fact in this regard is that antipsychotics are one of the few prescription drugs that a judge has the authority to force a patient to take for life (Inchauspe and Valverde, 2017).

In most cases, the suffering derived from SSPD has a devastating impact on the lives of those affected. This suffering increases with the many adverse effects of antipsychotics, such as extrapyramidal symptoms, risk of metabolic syndrome and cardiovascular disease, declining life expectancy, and cognitive and cerebral damage, among others (Inchauspe and Valverde, 2017). These effects occur both with typical (or first-generation) antipsychotics, which mainly cause extrapyramidal effects, and with atypical (or second-generation) antipsychotics, which produce fewer extrapyramidal side-effects but can lead to obesity and risk of metabolic syndrome, hinting at what Jenkins has called the "crazy or fat" paradox (Jenkins, 2015:65). Previously, in the era of typical antipsychotics and psychosocial rehabilitation, patients suffered from parkinsonism; now, in the era of atypical antipsychotics and recovery, they suffer from obesity.

Furthermore, antipsychotics show their usefulness in alleviating positive symptoms of psychosis (hallucinations and delusions), but do not work so well in tackling the negative symptoms (i.e. anhedonia, apathy, blunting of affect, and loss of motivation, among others) (Harvey et al., 2016), which are barely indistinguishable from the adverse effects of medication. In fact, patients may consider the side-effects of antipsychotics to be more relevant in their daily life than their therapeutic effects (Rodríguez del Barrio et al., 2013), thus contesting from their own experience what has been named the 'disease-centred' model of psychotropic drugs (Flore et al., 2019; Moncrieff, 2013). This set of limitations and dissonances between biomedical and lay explanatory models (see Kleinman, 1980) clearly restricts the possibility of supported decision making and collaborative management of medication.

The scenario is further constrained by obstacles in the social and psychosocial sphere that have been identified in the anthropological literature, both in earlier work dealing with first-generation antipsychotics (Estroff, 1985; Rhodes, 1984) and in later studies about recovery and second-generation antipsychotics (Brown, 2019; Jenkins, 2015; Choudhury et al., 2015). Jenkins (2015:65) and Jenkins and Carpenter-Song (2008:381) identify the two "paradoxes of lived experience" labelled "recovery without cure" and "stigma despite recovery." Together with the aforementioned "crazy or fat" dilemma, these two paradoxes encapsulate the contradictory predicament of those affected.

From the broader social science literature, we know that stigma expresses itself in manifold ways. People with a diagnosis of psychosis have work-related difficulties (Mangalore and Knapp, 2007), their network of social relationships is diminished (Degnan et al., 2018), they usually become dependent on their relatives (Awad and Voruganti, 2008), they suffer from social exclusion (Morgan et al., 2018), and their rights, including decisions about their health, are constrained (Rodríguez del Barrio et al., 2013). All these aspects combine to form a spiral of chronicity and exclusion that limits their lifeworlds and challenges the efficacy of current mental health policies.

1.1. *In search of an alternative model*

In recent years, alternative models have emerged with a focus on the reduction or cessation of medication, especially during initial episodes. Such is the case of Soteria in the United States and Switzerland (Bola and Mosher, 2003), the Swedish Parachute Project (Stralin et al., 2019), and the Finnish Need-Adapted Project (Bola and Mosher, 2003), which has influenced the consolidation of the Open Dialogue model in Finland. Some figures from this last initiative are encouraging: a five-year follow-up showed that 80% of patients had returned to their employment or study activities and reported a better quality of life and reintegration into the community (Seikkula et al., 2006).

Another of these alternative models is the *Gestion Autonome de la Médication en Santé Mentale* (Gaining Autonomy & Medication Management, hereinafter GAM), developed in the early 1990s by research teams in Quebec (Canada), and in collaboration with civil society, particularly with users of mental health care services and their advocacy groups (Rodriguez del Barrio et al., 2014). The GAM initiative has been recognised as best practice by the Health and Welfare Commissioner of Quebec, and since 2009 has also been implemented in Brazil through the *Alliance Internationale de Recherche Universités - Communautés, Santé Mentale et Citoyenneté* (Rodríguez del Barrio et al., 2013; Onocko-Campos et al., 2013).

The main objectives of the GAM initiative are to support: 1) the patient's access to information and education about medical treatments and rights; 2) person-centred care and sensitivity to the patient's illness experience; and 3) the promotion of collaborative actions to improve care and clinical communication (Rodriguez del Barrio et al., 2014). The GAM can be defined as a bottom-up initiative for supporting decision making on antipsychotic medication in clinical settings and beyond (i.e., family context, community, social networks) based on the recognition of patients' experiences, needs and rights, and the promotion of patient autonomy. In this vein, its approach shares some of its aims with other well-known models, such as person-centred care, the harm-reduction approach, the shared decision-making perspective or, more closely, supported decision-making initiatives (Stone et al., 2019; Simmons and Gooding, 2017). Nevertheless, the GAM model has some particularities derived from its bottom-up origin, such as its insistence on determining patients' needs in accordance with their own views and experiences, the inclusion of reflexivity through a patient diary as a tool for gaining autonomy, and the mobilisation of community resources in order to enable users to achieve full citizenship. In practical terms, the GAM initiative is set out in the *GAM Guide* (ÉRASME, 2017), which describes the steps towards developing the patient's autonomy and strengthening decision making about their own health. Some evaluations (Rodriguez del Barrio et al., 2014) of the GAM initiative in Canada have found benefits such as rationalisation of spending on antipsychotics, reduced risks derived from overmedication, and improved patient satisfaction. Other health and healthcare benefits include changes in the culture of care, greater satisfaction among professionals with their own clinical practices, modification of patients' lifestyles, and improvement of patients' autonomy and social inclusion.

Following in the footsteps of the GAM initiatives in Canada and Brazil, in 2017 our team started a participatory action project in mental health in Catalonia called the *Gestió Col·laborativa de la Medicació* (the Collaborative Management of Antipsychotic Medication or GCM). We opted to change the name from GAM to GCM since in Catalan and Spanish the notion of autonomous management could be misunderstood to be advocating self-medication rather than reinforcing patients' rights and autonomy. The main phases of our initiative were: 1) the ethnographic analysis of the obstacles to the collaborative management of antipsychotic medication in the Catalan public mental healthcare network; 2) the preparation of a GCM guide (still in progress) with the active participation of patients, family caregivers, and mental health professionals; and 3) the implementation of the GCM model in two mental health services. This article presents the results of the first phase of our initiative and aims to analyse the main obstacles to collaborative management of antipsychotics between patients, family caregivers and professionals. This study is the first GAM initiative in Europe.

Table 1
Characteristics of research participants.

	Male	Female	Total
Patients			
Recruitment location			
Nou Barris Adult Mental Health Centre	6	6	12
Badalona Adult Mental Health Centre	6	3	9
Other Mental Health Services	0	3	3
Associations	11	3	14
Total	**23**	**15**	**38**
Mean age (SD)	46.67 (11.06)	44.83 (4.88)	45,74 (7.966)
Mean years taking antipsychotics (SD)	19.33 (9.87)	17 (5.94)	18.17 (1.65)
Caregivers			
Recruitment location			
- Nou Barris Adult Mental Health Centre	1	3	4
- Badalona Adult Mental Health Centre	2	3	5
- Other Mental Health Services	1	3	4
- Associations	2	3	5
Total	**6**	**12**	**18**
Relationship with the patient			
Parent	4	10	14
Partner	2	2	4
Total	**6**	**12**	**18**
Mental health professionals			
Recruitment Location			
Nou Barris Adult Mental Health Centre	2	7	9
Badalona Adult Mental Health Centre	1	5	6
Other Mental Health Services	0	4	4
Total	**3**	**16**	**19**
Professional profile			
Psychiatrists	0	4	4
Psychologists	1	3	4
Nurses	2	1	3
Social Workers	0	4	4
PSI*(Individualised Support Programme)	0	4	4
Total	**3**	**16**	**19**

*PSI is a Catalan mental health programme for domiciliary and continuous care designed for people affected with severe mental disorders. The PSI professionals interviewed in this study were psychologists, nurses, physicians, and social workers.

2. Method

2.1. Design and sampling

The study was conducted between February and December 2018 in Catalonia and followed the COREQ criteria for qualitative interviews and focus groups in all its aspects (Tong et al., 2007). We interviewed 38 users of antipsychotics (two were interviewed twice), 18 family caregivers, and 19 mental health professionals (see Table 1). Participants were recruited from two mental healthcare services in Barcelona (Nou Barris) and Badalona, a city to the north of Barcelona. These two publicly funded centres serve low and middle-low socioeconomic populations that represent the linguistic diversity in Catalonia (mainly Catalan and Spanish); indeed, several patients and caregivers were from or had family origins in other regions of Spain. The professionals also reflected this linguistic and cultural diversity since some of them came from other Spanish regions, and three of them were foreigners who had settled in Catalonia more than ten years previously. The therapeutic approaches offered by the professionals working in these services include biomedical, psychodynamic, cognitive-behavioural (CBT), systemic family therapy (SFT), and open dialogue perspectives. Additional informants were recruited from two other mental healthcare services in Barcelona and Tarragona; the Mental Health Federation of Catalonia, which represents the set of associations (106 entities) of caregivers and professionals in Catalonia; and from patients' associations.

The inclusion criteria for recruiting patients were: a) to be a user of public mental health services; b) to have a diagnosis of a SSPD, and c) to have consumed antipsychotics for at least one year prior to recruitment. The caregivers had to live with a patient and the mental health professionals had to be in active employment. While the purpose was not to recruit a matched sample of patient-caregiver-clinician related participants, in some cases they had a caregiving (five participants) or clinical (nine participants) relationship. All the appointments and interviews were conducted individually and anonymously in order to avoid any ethical conflict. All users were taking atypical antipsychotic treatments and were in psychotherapy (mainly CBT, SFT or psychodynamics). More than half of the patients participated in the "individualised support programme", which involves follow-up at home by a health or social worker.

Although it was a sample of convenience, efforts were made to strike a balance between participants with an activist background, who are generally more critical of the administration of antipsychotics, and non-activist participants. We also attempted to ensure that the family caregivers had different roles (i.e. mother, father, husband, spouse/partners) and, whenever possible, gender parity. Three patients declined to participate for medical reasons; two relatives were unable to take part due to caring for a person in relapse, and two professionals withdrew because of scheduling conflicts.

The study was approved and monitored by the Open University of Catalonia Committee for Ethics in Research. The research was carried out in accordance with the ethical standards established by the Helsinki Declaration of 1964 and its subsequent amendments. Additionally, the research was supervised by a purposely created internal body attached to the project made up of patients, caregivers and professionals, the DoingResearchWith Committee (in Catalan: *Comité FerRecercaAmb*), whose function was to ensure that the participants' rights were respected throughout the research process. All participants expressed their willingness to participate by signing consent forms.

2.2. Interviews

We designed three separate semi-structured questionnaires, one for each group, in Catalan and Spanish, with both common and specific questions. The central common theme was the obstacles to collaborative management of medication as perceived by each group. This information was contextualised with questions on patient, caregiver and clinical experience. Three teams conducted the interviews. The first carried out fieldwork in Nou Barris Adult Mental Health Care Centre; the second in Badalona Adult Mental Health Care Centre; and the third in the rest of the services and civil associations. The seven interviewers, all of whom were researchers in medical anthropology, and/or medicine, psychiatry, psychology, social pedagogy and social work, participated in two preliminary working sessions to coordinate the fieldwork. Interviews were carried out in Catalan or Spanish, and at their convenience, in participants' homes, civic centres, coffee shops, or mental health service settings. The face-to-face interviews were audio recorded and lasted between 60 and 90 min. One professional declined to be recorded.

2.3. Focus groups

To triangulate the results of the interviews, ten focus groups, each with 6–14 participants, were conducted with patients (five groups), caregivers (three groups), and professionals (two groups). All groups were conducted by at least two researchers, and 65% of the focus group participants had also taken part in the individual interviews. The focus groups began with a vignette aimed at opening a debate on the obstacles to and challenges for the collaborative management of antipsychotics among participants. Their purpose was to jointly corroborate the main results of the individual interviews. All the focus groups were audio recorded.

2.4. Data analysis

All interviews and focus groups were transcribed and subsequently coded together using the MAXQDA 2018 software (Verbi Software, 2017). To ensure inter-reliability and reflexivity in the coding process, each researcher performed her/his own coding of a pre-established sample of the transcriptions from a hermeneutic and ethnographic perspective, including the discovery of emic semantic networks, and drafted a reflexive assessment. Subsequently, the individual codes were agreed upon, first within each work team, and then among the three teams through several joint meetings to determine a coding framework, discuss disparate cases, and evaluate the researchers' reflexive accounts during the fieldwork. The resulting coding tree was applied to all the interviews and focus groups, and its inter-reliability was then tested by cross-coding a sub-sample of transcriptions.

We detected three main obstacles to the collaborative management of antipsychotics: 1) adverse effects of the medication, 2) (un)awareness of the disorder, and 3) coercive communication models, including the undervaluing of patients' rights. After the analysis, the preliminary results were presented in two meetings with a selection of participants; this process allowed us to conclude that the point of saturation had been reached and it was not necessary to recruit additional informants.

3. Results

The obstacles detected in our study are transversally affected by other factors that emerged from our analysis, such as stigma related to SSPD, lack of human and economic resources in the mental healthcare system, and the organisation of services, and should not be understood as watertight compartments, but as strongly interrelated with each other. In what follows we present an analysis of these three obstacles from the perspectives of the different actors. A more extensive selection of extracts from the fieldwork supporting the results of this research can be found in Table 2 of the supplementary data appendix.

3.1. Obstacle 1: the adverse effects of medication

The three groups expressed difficulties in differentiating between the adverse effects of antipsychotics and the symptoms derived from the disorder, but each in a different way. Patients tended to deal with this uncertainty by associating distress to medication while professionals attributed it to the disorder, especially to the negative symptoms of the disease. Caregivers oscillated between these two perspectives. This discordance strained the communication between the actors involved and the collaborative management of medication.

3.1.1. The patients' view

The medication was a central factor in the patients' daily lives, whereas the disease was associated more with episodic relapses and admissions than with the negative symptoms of the disorder, which were usually interpreted as adverse effects of the antipsychotics. Three cases reported a satisfactory experience with medication and no side-effects. Twenty-four patients highlighted some positive outcomes, such as sleep regulation, mitigation of delusions and hallucinations, and stability in their daily lives. However, most of the patients, including those who recognised some positive results, expressed degrees of dissatisfaction that ranged from critical attitudes to resignation. The same individual might express both attitudes, leading to an ambivalence between the role of medication in avoiding relapses –the fear of hospital readmission was a constant theme in their narratives– and weariness with the adverse effects. In most cases, they experienced drugs as a source of suffering rather than as a path to recovery. Among the most critical participants, especially those with an activist background, antipsychotic treatment was experienced as a coercive imposition and an annulment of the self.

Adverse effects included "dullness" that caused them to "live like a zombie" and "not feel" the flow of life, to the loss of the emotional world and difficulties in social interaction. As an example, one informant reported feeling more alive when she was sleeping than when she was awake because she felt she was constantly living in a dreamlike nebula (Female Patient 41). Other adverse effects were lack of concentration, memory and attention, extreme drowsiness and tiredness, anxiety and restlessness, slowing down of the body, loss of mental and physical agility, obesity and fluid retention, inactivity that led to staying at home and isolation from the world, especially among men, and sexual disorders such as lack of libido, erectile dysfunction and anorgasmia. Antipsychotics can also cause gynecomastia in men, menstruation disorders in women, and galactorrhoea in both sexes because of increased prolactin levels. Other adverse effects were body stiffness and tremors.

In general, patients reported a tortuous path in their search for medical adjustment, involving admissions, readmissions and prescription changes that caused uncertainty and frustration. They described feeling like "guinea pigs" in "an experiment" or in "a labyrinth" (Male Patient 19), attributed their crises to medication changes (Male Patient 38), felt they were passive recipients of "trial and error" testing (Male Patient 39), or simply relegated their expectations from medication to a random future. One of the participants used the metaphor of a traditional game to illustrate this last feeling:

You know that game where there's a thing hanging full, a drinking jug [*botijo*] full of water, and you are blindfolded and you have to smash the drinking jug with a stick? That's what a psychiatrist does. Or, in other words, strike blind. (Male Patient 37).

In this context, patients can try ways of self-managing and discontinuing medication that, in some cases, will lead to new relapses and, in the long term, will bring about a state of resignation. Assuming the medication was "the price to pay" (Male Patient 23) because "coming off it is worse than being medicated" (Male Patient 20), it was a "band-aid" solution to carry on living (Male Patient 32), the necessary and at the same time painful support to maintain psychic stability, because without medication you "lose control" and "you don't know where to hold on to" (Male Patient 39), or they simply considered that they could no longer "live without medication" (Female Patient 14). However, the doubt often remained about the real effects of antipsychotics, because as one informant stated, "I don't know if these psychotic episodes stopped because of the medication or because they just stopped" (Male Patient 39). In these cases, distrust in medication was revealed as the counterpart to the biomedical disease-centred approach and its related trust in pharmaceuticals (Moncrieff, 2013; Flore et al., 2019).

3.1.2. The professionals' view

Unlike the patients, the professionals gave less importance to the adverse effects of the medication, although this does not mean that they undervalued them all together. These effects included sexual dysfunctions, parkinsonism, drowsiness, obesity, metabolic syndrome and, to a lesser extent, dullness, slowing down and cognitive delay and damage, which mental health workers frequently interpreted as negative symptoms of the disorder. They generally considered that adverse effects and negative symptoms could not be distinguished with full certainty and, as a result, they tended to focus on the positive symptoms and disregard negative symptomatology. The professionals reported that medications were compensatory but not curative, and that the same antipsychotic could work differently with the same patient depending on their biographical period, changes in the "natural history of the disease" or in the "interferences" that can cause everyday life, familial and interpersonal problems. Faced with such uncertainty, some valued clinical "intuition" (Professional Psychiatrist 8) as well as strategies such as revising medication, continuing it through a logic of *faits accomplis* (Professional Psychiatrist 4) or, in other cases, reducing the doses of the antipsychotics. This last strategy was mainly observed among professionals who took a more proactive attitude to a collaborative model, although such initiatives pulled them out of their comfort zone and forced them to deal with "uncertainty."

3.1.3. The caregivers' view

Caregivers were the group that oscillated most between attributing discomfort to the medication or to the illness and, in so doing, they positioned themselves as brokers. Caregivers who attributed the cause of the patient's distress to antipsychotics were those who inclined towards more dialogic communication and the recognition of patients' rights (three caregivers). Alternatively, those who attributed the patient's distress to the symptoms of disease accepted more coercive models (thirteen caregivers). In both cases, the main adverse effects reported were sedation, problems of memory and concentration, drowsiness, fatigue, inactivity, isolation, and the "annulment" of patient self. They also described other adverse effects such as toxicity, obesity, tremors, gynecomastia in men, restlessness, insecurity in social relationships, erectile dysfunction, and bodily stiffness.

According to the caregivers, in the everyday context "medical sedation" was the way to ward off the risk of a new relapse, although this adverse state could negatively affect their image of the patient, who they observed, first with astonishment and then with resignation, as a "new person". In these moments, caregivers perceived patients as dull, transformed, clumsy, unrecognisable in comparison with what they were able to do in the past, defeated, "a piece of furniture" (Female Caregiver 3), "a vegetable" (Male Caregiver 12) or as an "object more than a subject" (Female Caregiver 16). This last informant recalled the shocking image of her son's first psychiatric admission, trembling and drooling after the treatment, and voiced her doubts on whether the adverse effects were worse than the disorder itself. For some caregivers, the nature of the transformation was such that they experienced it as grief for their lost son or daughter. Fear, guilt and resignation create an emotional arena among caregivers that fosters mistrust, vigilance over adherence to treatment, and coercion, as well as poor expectations about the patient's autonomy. In this context, the affected relative may be regarded as a permanently ill person with uncertain symptoms and unpredictable behaviour, thus eroding the horizon for shared decision making about medication.

3.2. Obstacle 2: (un)awareness of the disorder

For all the groups, the patient's unawareness of the disorder was a challenge, particularly in the first episode and early stages of the illness, but again evident dissonances emerged in dealing with the poor insight of those affected. While the professionals, and to a lesser extent the caregivers, complied with the traditional definition of the awareness of the disorder concept in the psychiatric literature: awareness of illness, need for treatment and relabelling of symptoms (Amador et al., 1994), patients showed a different insight that here we will call "awareness of suffering". This notion takes on a broader definition than the strictly biomedical view since it includes various sources of suffering that are not limited to the disorder. For caregivers, awareness of the disorder was synonymous with self-care.

3.2.1. The patients' view

The patients' awareness of suffering included a set of discomforts arising from the disorder, but mainly from the adverse effects of medication, their lived experiences in psychiatric admissions and the social consequences of their mental condition: stigma and marginalisation in the social arena, among others. Their idea of suffering did not always include psychotic episodes prior to treatment, which may even be perceived as pleasurable: "A person who is not aware [of his/her disorder] is having a good time" (Female Patient 11).

According to the patients, the refusal to accept the disease comes from the mental disorder itself, which prevents them from recognising their condition, but it is also a result of the experience of stigma and the coercive measures in admissions. Sometimes, this denial was a way to "turn the page" or "to start a new life" (Patients' Focus Group 5) and to demonstrate to themselves that they could control their discomforts and symptoms, particularly when they began to feel well and the episodes of relapse had become a memory (Female Patient 5). Among patients, unawareness of the disorder commonly responded to expectations of recovery and overcoming the disease. In this sense, it can be understood as an attempt to unravel the series of daily conflicts and events that limit their lifeworlds.

As our informants indicated, poor insight into the disorder was more frequent among men and in the early stages of their illness, including first admissions. Importantly, they did not perceive acute psychiatric care units as a healthy locus, but a place of suffering. Subsequent episodes and readmissions led to a state of depression and blunting, which was often attributed to medication, and again to denial or, over time, acceptance of the disorder. However, they continued to disagree with the perception of professionals, mainly when they considered they were not being well cared for, or because of hierarchical communication models that made them feel judged or undervalued. In some cases (e.g. Male Patient 35), they specified that professionals' insistence on awareness of the disorder was a pretext for overmedication and coercive practices and reflected a disregard for other aspects of their lives that caused them suffering, such as the diagnosis itself operating as a semantic and existential ascription which, by naming the affliction, acted as a barrier to full citizenship. They also considered that this clinical insistence on the disorder was used to remind them of their sickness, fostering what we can define here as the "total patient" effect or the reduction of the affected person to a diagnostic category. As one of the participants stated, "People usually think that when a person suffers from a disorder, they have a permanent disorder. They don't. A person who has paranoid schizophrenia is not hearing voices every day" (Male Patient 7). According to those affected, this reductive perception was the main cause of professionals' and caregivers' lack of awareness of the patient's "real" suffering and its multiple sources.

3.2.2. The professionals' view

Mental health workers agreed with patients that it is difficult for a person, especially if they are young and do not experience their problem as a dysfunction, to accept they have a mental disorder which requires continuous or lifelong use of medication that will affect many areas of their life: social relationships, employment, and expectations for their future. Nevertheless, they considered awareness of the disorder to be the touchstone for treatment success. Some of them recognised that focusing on the disease led them to neglect other adjacent forms of suffering (e.g., admissions, adverse effects, problems derived from the stigma) and to wait uncritically for the patient's adherence and compliance. One professional, a psychiatrist (Professionals Focus Group 1), affirmed that the problem with "the awareness of disorder" conceptualisation was the emphasis on the disorder rather than on mental health. Another psychiatrist alluded to the "awareness of suffering" to show the potential dissonance between the expert view of the problem and that of the affected person (Professionals Focus Group 2). A third professional, a social worker, criticised the nature of the messages associated with awareness of the disease and lifelong treatment since they encourage the idea of illness chronicity (Professional Social Worker 7). However, the general trend among mental health workers was to consider the patient's insight as a precondition for a therapeutic alliance and they even strongly associated patients' complaints about adverse effects of medication with disorder unawareness. For most mental health professionals, awareness was synonymous with patient's compliance.

3.2.3. The caregivers' view

For the caregivers, unawareness of disorder was a threat to family life and a source of interpersonal conflicts. Their role usually included supervising the patient's compliance with medical prescriptions, a task they understood as a "lesser evil" to ensure a harmonious family atmosphere. They considered that if patients recognise their sickness, it means that they also accept the treatment in all its terms because cessation of medication would entail a clear risk of relapse. Caregivers experienced this risk with extreme anguish because past episodes had involved suicide attempts, disruptive behaviours, and in one case even sexual assault (Female Caregiver 11). They saw time as an ally, understanding that as time passes, patients move away from their position of "rebellion" and "denial" and accept that they have a disease that requires adherence to treatment, but also self-control and self-care, such as attending therapeutic meetings and medical visits, not drinking alcohol or consuming recreational drugs, and following a daily routine (i.e. hygiene, sleep, exercise). They stated that in addition to the disorder itself, adverse effects and stigma were factors that hindered awareness of the disorder among those affected. This led them to try to "lighten" the disease in their daily communication with patients, through comparisons with other chronic diseases such as diabetes, even if this strategy led to a lack of empathy with the perception of those affected. In one focus group, two participants notably disagreed with the other caregivers, outlining the medical risks of antipsychotics and the use of "unawareness of disorder" by clinicians and family members as an excuse for overmedicating patients. These informants also criticised the caregiver's role as "the elongated controlling arm of the psychiatrist".

3.3. Obstacle 3: coercive communication models

Communication problems were clearly an obstacle and a challenge for our three groups of participants, but again there were discordances among the explanatory models in play. These dissimilarities can be condensed in the different meanings in Spanish (and in Catalan) of the words "*trato*" (*tracte* in Catalan) and "*tratamiento*" (*tractament* in Catalan) (Leal Rubio, 2018). *Trato* or *buen trato* means both having a pleasant manner and dealing with or agreeing with someone and presupposes an intersubjective relationship as well as negotiations with another person. In contrast, *tratamiento* denotes handling and management and is mainly applied to the action of a subject on an object. In short, we can say that patients expected to receive a kind *trato* that was sensitive to the problems beyond their medical condition and that allowed them some room for negotiation, including the recognition of their rights. Here *trato* comes close to the notions of concordance and supported decision-making. By contrast, the professionals emphasised psychotherapeutic and medical treatments and tended to underestimate the informal dimensions of coercion. Finally, and with some exceptions, caregivers understood coercive behaviours as a means to ensure patients' obedience and avoid a disruptive family environment.

3.3.1. The patients' view

The patients recognised that when they are in relapse, optimal clinical communication is not easily achieved. Nevertheless, even in these cases they insisted that the clinical response should not be one of coercive measures and high doses of medication, but dialogue to help them accept and manage their suffering, together with low doses of antipsychotics to allow them to maintain their decision-making capacity. In their view, good *trato* can be defined as proximity, empathy, dialogue, negotiation, feeling that their vital needs are heard and receiving unhurried attentive information about their disorder and the effects of medication, especially when they are under polypharmaceutical treatment. Nevertheless, eleven patients reported that they preferred not to receive information about their medication and that they did not want to read drug leaflets because they had chosen to forget their experience of the disease and avoid being psychologically influenced by the information about the side-effects of the medical treatments.

Patients were aware that the lack of medical information was due to the professional fear of jeopardising adherence. However, they missed a kind of communication that prioritises continuity of care over control, vigilance, distrust and hierarchy. In this sense, they placed a very high value on their relationships with nurses and with the professionals involved in individualised support programmes designed to create a bond of care and trust over time. One of the patients stated that he could hardly trust his psychiatrist if the professional did not trust him (Patients Focus Group 1). Some of them also wondered to what extent the clinicians took what they said seriously, because the professionals might wrongly interpret their demands as distortions caused by the disease (Male Patient 38). One of the patients expressed himself in these terms, "We've developed a survival attitude. We can distinguish clearly between a professional seeing a disease and a professional seeing a person" (Male Patient 38). This testimony clearly illustrates the disparity between *tratamiento*, the handling of the disease, and *trato*, the intersubjective relationship that encourages their recognition as individuals with autonomy and citizenship. Several patients (seven) were in favour of making or had already made advance directives to safeguard their rights in the case of a new psychotic episode.

3.3.2. The professionals' view

The professionals stated that providing complete information to patients about the adverse effects of medication could lead to a risk of discontinuation. According to one professional, "unconsciously, we are all afraid that patients will abandon the treatment" (Professionals Focus Group 1). This perceived risk leads to the contradiction between their agreeing to give full clinical information and recognising patients' rights, and not informing, providing only partial information or adopting the logic of *faits accomplis*. This contradiction between discourses and actions does not imply that the professionals were unaware of patients' needs and expectations, but that they felt they lack the resources necessary to face an increasing demand for care, which limits the clinical follow-up of those affected.

Assuming a role based on negotiation and dialogue was perceived as an improvement in clinical practice and, at the same time, as an additional personal burden, even among highly motivated professionals who observed that medical and psychotherapeutic treatments might require substantial efforts with no guarantee of clear clinical outcomes. Collaborative communication models were valued positively, even though they entailed more uncertainty and obliged them, as one nurse put it, "to be more fluid" and adaptable to changing situations (Professional Nurse 15). They criticised the lack of clinical positions in the public services as one of the structural impediments to dialogic communication in the clinical setting and identified potential solutions, such as coordinated teamwork, support for families and the strengthening of trust in the clinician-patient relationship. One psychiatrist claimed the current care system was flawed because of its bias towards medical interventionism rather than addressing patients' needs, and that the inclusion of the open dialogue model in his service had dramatically changed his professional life (Professionals Focus Group 1). Another psychiatrist appealed to humanising clinical practices to increase effectiveness (Professionals Focus Group 2). Several professionals (6) commented during the focus groups that participating in this study had led them to change their therapeutic practices and advocated giving space for reflexivity both in the clinical team and in their relationship with patients and caregivers.

3.3.3. The caregivers' view

According to the caregivers, when a patient relapses the whole family goes into crisis, to the point that the caregivers feel helpless due to lack of clinical information, especially in the early stages of caring. As one of the participants said, "families feel totally lost and helpless. It's such a huge drama!" (Female Caregiver 11). Another informant summarised his uncertainty, arguing that caring for a person diagnosed with schizophrenia was like "treating something that is not understood as though it were understood" (Male Caregiver 12). Faced with this uncertainty, caregivers found it difficult to understand why professionals kept clinical information from them on the grounds of the patient's right to confidentiality.

In general, the caregivers described tortuous caring processes that could lead to clearly coercive communication models, such as strict monitoring of medication compliance, limitation of patient autonomy, compulsory admissions, hiding medication in food, complaints to the police, threats of home expulsion or requests for legal incapacitation if the patients failed to follow the rules. These actions must be interpreted as embedded in a cultural code that, while objectifying those affected as a "vegetable" or a "piece of furniture", justifies a relationship based on coercion and "handling", and, in turn, narrows the horizon of good "*trato*" as the cultural ground for the re-subjectivation of relationships in the family context. Thirteen of the caregivers reported clearly coercive attitudes in their care itinerary. The most common motive was that when patients are in psychotic relapse, negotiation becomes impossible because they are unaware of the disorder. Likewise, we saw traces of resistance in some narratives: three caregivers advocated using alternative communication models based on dialogue, and two of them openly supported a new culture of caring which does not stifle patients' autonomy.

4. Discussion

This study is the first GAM initiative in Europe. The obstacles detected reveal the difficulties of assuming clear lines between symptomatology, adverse effects and illness experiences (Flore et al., 2019), and uncover the profound disorientation produced by a devastating disorder, medication with poor outcomes, and a stigmatised self despite possible recovery (Jenkins and Carpenter-Song, 2008). In her ethnography on the Clozapine clinic in the United States, Jenkins (2015) defined the bewilderment that accompanies schizophrenia and psychotic states by affirming that the experience of this type of "extraordinary condition" can be as incommunicable and incomprehensible "to those so afflicted no less than to the unafflicted" (2015: 261). This statement is congruent with our data. One of the caregivers in our study described the process as handling something that is not understood as if it were. Then again, one patient affirmed that we cannot understand such experiences with a rational code when they are in fact written in emotional language. In both testimonies, as in others gathered in this study, there is a palpable problem of indeterminacy surrounding the medication, the disorder and the patient's self that depicts a scenario of anticipation, suspicion and mistrust. This setting paves the way for coercive practices and hinders the collaborative management of antipsychotic medication.

According to Verbeke et al. (2019), coercion is embedded within an intersubjective context and involves the de-subjectivation of those affected. This process implies a reduction of their subjectivities to the condition of patients. Indeed, many of the patients' comments in our study lay in this direction. The patients highlighted a social and clinical failure to recognise them as individuals with autonomy and agency, either in their decisions regarding medical treatments or in the broad spectrum of their lives, since the conflicts with medication become a synecdoche for their existence and mobilise morals worlds that have profound effects on the sense of self.

In our study coercion was sometimes unambiguous, for instance when medication is hidden in food. On other occasions, however, it was surreptitious, such as when patients are not informed about the adverse effects of medical treatments or about their rights, or when the patient's voice is overlooked in day-to-day decisions, whether banal or consequential, but that in any case have a cumulative erosive effect on the self. Caregivers' perceptions of those affected as "vegetables", a "piece of furniture" are expressions of this structural coercion. It is also present in professional attitudes such as overmedication and the kind of clinical treatment that objectifies patients and transforms them into nosologies. This de-subjectivation is precisely what the patients in our study challenged when they contrasted the *trato* with the *tratamiento*. While the former expresses the hope that they will be recognised as subjects, the latter evokes the idea of a permanent or "total patient" in need of total therapy.

Motivated by Goffman (2017) classic concept of the total institution as places that absorb the set of behaviours of the individuals who live there together, such as the asylums prior to psychiatric reform, here we propose the idea of the "total patient" to express the reduction of the self to its condition as patient, in such a way that this identity absorbs the affected person's life in its totality. In this vein, it has parallels with other notions such as dehumanisation (Kontio et al., 2012), or de-subjectivation (Verbeke et al., 2019). The identity is reduced to a very specific one in which the damaged self is perceived as a psychopathological island requiring total therapeutic intervention or total therapy. The phenomena of the total patient and total therapy clearly limit the possibility of dialogue. Patients see themselves as "zombies" induced by antipsychotics (see also Flore et al., 2019; Werremeyer et al., 2017; Morrison and MeehanStomski, 2015); their caregivers see them as a "piece of furniture" without autonomy, and professionals see them primarily as "disorders", thus encouraging the primacy of nosology over illness narrative; bureaucratic pigeonholing over biography; technical treatment over human needs.

Clinical practices based on the preconceptions of the total patient and total therapy also affect how the afflicted person perceives professionals. As we have seen, one patient described the "survival strategy" he had developed to discern whether the professional is looking at a person or a disease. The notion of strategy can be understood here as defensive anticipation of possible de-subjectivation. However, it also includes the possibility that the professional can be recognised as a person with whom one can enter into dialogue, and the clinical interaction as a space of mutual recognition and, therefore, of collaboration. Despite their coercive actions, this attitude was also present among caregivers, who feel helpless, but at the same time want spaces where they can express their everyday anguish and foster collaboration, interaction with professionals and shared responsibilities with them and with those they are caring for.

The results of our research are consistent with previous studies (Elmer et al., 2018) which suggests that mental health professionals tend to underestimate informal coercion. However, the professionals in our study also expressed interest in humanising the clinical setting by fostering empathy, developing relationships of trust with the patient, and sharing decisions with patients and caregivers. Many of the professionals also felt de-subjectivated by the healthcare burden caused by the scarcity of resources that turns them into mere dispensers of diagnoses and medical treatments.

Verbeke et al. (2019: 95) state that "if we want to reduce coercion in psychiatry, we cannot simply tackle specific techniques but must tackle the power dynamics within which they are embedded". In the same way, if we want to promote a model of collaborative management of antipsychotic medication, we must encourage a new culture of care and recovery with all the actors involved, including taking into consideration the multiplicity of voices and perspectives among patients, caregivers and clinicians. A first step, as noted by Rodriguez del Barrio et al. (2014), would be to evaluate services and public policies according to their ability to safeguard users' rights and to promote mutual collaboration, and not only as dispensers of medical and psychotherapeutic treatments. This would imply recognising good *trato* as a consubstantial basis for any good treatment.

4.1. Limitations and strengths

The results of this study should be considered with caution. Despite our efforts to extend our sample to a range of patients, caregivers and professionals in Catalonia, the bulk of the research was carried out in two specific mental health centres which showed a strong commitment to rethinking their models of medication management and clinical communication. This basis was a precondition since the study was dependent on a subsequent intervention conducted in two phases: 1) formulating a GCM guide adapted to the Catalan context with all the actors involved, and 2) implementing this initiative through a pilot project in the aforementioned services. Given these circumstances, it may be expected that the obstacles to the collaborative management of antipsychotics will be more significant in other services in the Catalan mental healthcare network. On the other hand, the strengths of this research can be seen in the changes that have already taken place in the participating services. In the two meetings we held with informants to present the preliminary results of this research, professionals and caregivers explicitly highlighted that participation in the study had led them to rethink their professional and caregiving practices, and to reconsider how they relate to the patients. This may be a manifestation of the subtle potential of ethnographic and qualitative research to stimulate changes in social worlds.

Author contributions

Ángel Martínez-Hernáez: Conceived and designed the analysis, Collected the data, Contributed data or analysis tools, Performed the analysis, Wrote the paper. Asun Pié-Balaguer: Conceived and designed the analysis, Collected the data, Contributed data or analysis tools, Performed the analysis, Wrote the paper. Mercedes Serrano-Miguel: Conceived and designed the analysis, Collected the data, Contributed data or analysis tools, Performed the analysis, Wrote the paper. Nicolás Morales-Sáez: Conceived and designed the analysis, Collected the data, Contributed data or analysis tools, Performed the analysis, Wrote the paper. Andrea García-Santesmases: Conceived and designed the analysis, Collected the data, Contributed data or analysis tools, Performed the analysis, Wrote the paper. Deborah Bekele: Conceived and designed the analysis, Collected the data, Contributed data or analysis tools, Performed the analysis, Wrote the paper. Elisa Alegre-Agís: Conceived and designed the analysis, Collected the data, Contributed data or analysis tools, Performed the analysis, Wrote the paper.

Acknowledgments

The project The Collaborative Management of Antipsychotic Medication: A Participatory Action Research Project in Mental Health has received funding from RecerCaixa-Obra Social La Caixa (Grant ID:LCF/PR/RC16/10100012). We are grateful to our informants for their generous support, comments and criticisms. We also wish to thank the participant institutions for their unfailing commitment, specifically, Nou Barris and Badalona Mental Health Care Centres, Mental Health Federation of Catalonia, Catalan Mental Health Congress Foundation, Radio Nikosia Sociocultural Association, Aixec Cooperative, and La Muralla. Finally, we thank the three anonymous reviewers whose comments/suggestions helped improve and clarify this article.

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.socscimed.2020.112811.

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