



## Experiences with Mental Health Services: perspectives of diagnosed people in Catalonia, Spain

*Experiencias con los Servicios de Salud Mental: perspectivas de las personas diagnosticadas en Cataluña, España*

Liana Cristina Dalla Vecchia Pereira  
Carlos Alberto Severo Garcia-Jr  
*Federal University of Santa Catarina*

### Abstract

The field of mental health is marked by social exclusion, stigmatization, discrimination by society and violation of human rights; aspects that constitute significant challenges for national and international development in public health. In this phenomenological study, from the perspective of social representation, we interviewed 12 people diagnosed with a mental disorder in Catalonia, Spain, to investigate their experience with mental health services. Most experiences with health services were marked by a hierarchical model in power structures, in which the perspectives of people diagnosed were delegitimized. The legitimacy of specialized and public representations about mental health shaped the lives of the participants, as they felt voiceless and impotent, having their representations subjugated. Constructive experiences were related to being heard, cared for and understood by health professionals. By considering people diagnosed with a mental disorder, significant contributions can be made to improve the provision of comprehensive, effective and sensitive mental health care.

Keywords: **Mental Health Services; Mental Disorders; Delivery of Health Care; Spain**

### Resumen

*El campo de la salud mental enfrenta desafíos significativos como la exclusión social, estigmatización, discriminación y violación de derechos humanos, tanto a nivel nacional como internacional en salud pública. En este estudio fenomenológico realizado en Cataluña, España, desde la perspectiva de la representación social, se entrevistó a 12 personas diagnosticadas con trastornos mentales para explorar sus experiencias con los servicios de salud mental. La mayoría describió experiencias marcadas por un modelo jerárquico en las estructuras de poder, donde sus perspectivas fueron deslegitimadas. Las representaciones especializadas y públicas sobre salud mental moldearon sus vidas, dejándolos sentirse mudos e impotentes frente a estas representaciones dominantes. Las experiencias positivas surgieron cuando fueron escuchados, atendidos y comprendidos por los profesionales de la salud. Considerar las voces de quienes tienen diagnósticos de trastornos mentales puede significar mejoras sustanciales en la prestación de atención integral, efectiva y sensible en salud mental.*

Palabras clave: **Servicios de Salud Mental; Trastornos Mentales; Atención a la Salud; España**

## INTRODUCTION

Mental ill-health is highly common in all regions of the world and affects every age group and community, across countries of all income levels (World Health Organization [WHO], 2010). The field of mental health has been marked by social exclusion, stigmatization, discrimination and violation of human rights; aspects that hinder the achievement of the highest attainable standard of health and well-being. People with mental disorder often have their views delegitimized and are denied civil and political rights, limiting their personal liberty in many life aspects, as well as exercising their legal capacity, including their treatment and care (WHO, 2013). This scenario constitutes a significant challenge to achieving national and international development goals in public health. Multisectoral promotion and prevention strategies are needed at all stages of life to transform mental health. Therefore, it is essential to explore some of the intervention options available to reduce risk and build resilience at an individual, social and structural level (WHO, 2022).

Considering the complexity of mental health subjects and particularly the fact that diagnosed people often have their views de-legitimized, this study aimed to investigate the perspectives of people diagnosed with a mental disorder in their experiences with health services and to explore how social representations shaped their lives.

### **Prevalence of Mental Illness and the Spanish Health System**

About a quarter to a third of the population suffer from mental distress every year in Europe, in which neuropsychiatric disorders are the third leading cause of disability-adjusted life years (DALYs), accounting for 15.2% (WHO, 2015). There is a 10-25 year life-expectancy reduction among people with severe mental disorders (WHO, 2014). In 2020, around 22% of the Spanish population suffered from at least one mental health condition. Since 2020 and as a consequence of the Covid-19 pandemic, mental health has been increasingly affected throughout the world. It is estimated that Spain has had a high prevalence of depression 27% and anxiety 25% in recent years (ISGlobal, 2023).

Although the prevalence of mental illness is high, health systems have not yet adequately responded to the burden of mental distress; as a consequence, there is a gap between the need for treatment and its provision all over the world (WHO, 2013). Even in countries with a mental health system considered to be more appropriate, the healthcare provided did not yet respond adequately to the users' needs. There are significant discrepancies on how mental ill-health is understood and represented among the different social actors, and those diagnosed are often voiceless and powerless. In this sense, it is substan-

tial to consider people's experience with mental health services and professionals. They can also be powerful advocates for people-centred initiatives and recovery-oriented mental health care based on human rights and for policies and legislation to protect these rights (WHO, 2022).

The care of people with a mental disorder has been reformed in many countries, which is known as psychiatric reform. Institutional care within a historical context of marginalization of the *mentally ill* through asylum has been replaced by community-based care, representing a major change in societal reactions to mental illness since the beginnings of confinement in the seventeenth century (Morant, 2006).

The Spanish Health System (SHS) is universal since the General Health Care Act of 1986, in which access to healthcare became free at the point of use with co-payments restricted to pharmaceuticals. The de-institutionalization of long-stay psychiatric hospitals (asylums) was initiated in the late 1970s and the Psychiatric Reform Act was held in 1985 in Spain, which contributed to the development of community-based mental healthcare. This change involved the development of an out and inpatient facilities such as mental health centres, community rehabilitation services, protection of job reinsertion and the social club - activities provided by user-led or family-led associations (Bernal-Delgado et al., 2018). Nonetheless, Julio Bobes et al. (2012) states that this shift away from institutional to community-based care has been markedly uncoordinated with asylum closures before community services have been fully developed.

Although the community-based care requires integration of diagnosed people, most studies regarding the interactions established within the community were mediated by negative representations and stigmatizing attitudes towards people with mental illness (Chen, 2021; Costa-Font et al., 2008; Foster, 2001; Lacerta & Santos, 2020). Stigmatizing representations of mental health may lead to strategies of avoidance and discrimination, reiterating the importance of investigating how social representations shape diagnosed people's lives. Furthermore, stigma and treatment experiences impact in seeking mental health care (McLaren et al., 2023).

### **Mental Health and Social Representations**

The world of mental health is culturally embedded and shaped by social processes characterized by the development and circulation of social representations (Morant, 1995). The position of people labelled as *mentally ill* within the community is mediated by a complex web of factors and cultural constructs which moderate social practices and interaction based on different knowledge systems and understandings.

According to Serge Moscovici (1973), the concept of social representations is used to explain the construction of particular systems of values, ideas and practices of different societies with a twofold function: of establishing an order which enables the individuals to orient themselves and to communicate in their social group through the use of codes; by naming and classifying the various aspects of their worlds. These codes, or representations, permeate social relationships, cultural practices and power relations (Howarth et al., 2004).

Several studies identified the consistency of social representations of mental illness that are historically associated with themes such as otherness, strangeness, unpredictability, dangerousness, threat, and linked with negative views of deviance and abnormality (Angermeyer & Dietrich, 2006; Chen, 2021; Dixit, 2005; Foster, 2001; 2003; Jodelet, 1991; Lacerda & Santos, 2020; Zamorano et al., 2023). These representations are loaded with emotions of fear, anger, blaming for the psychological problem, leading to discriminatory and avoidance behaviours (Zamorano et al., 2023). In this way, the social stigma can cause individuals and groups to reject, exclude and separate themselves from those considered *mentally ill*.

With regard to health-related practices, a major change in mental health care in Western countries was the replacement of institutional care towards a community-based model, demanding social integration despite the historical context of marginalisation through asylums (Foucault, 1967). The psychiatric hospitals (asylum or madhouse) were commonly built in the countryside, reinforcing representations of the mad as threatening and frightening: others who must be kept locked away from normal and sane society (Foster, 2013). The structural change from an asylum-based toward a community-care approach was not enough to promote the full social integration of diagnosed people and to modify the stigmatizing, tutelary and exclusionary practices, since some hierarchical knowledge systems prevail in this field (Howarth et al., 2004). Indeed, the authors point out that, even when those perspectives are questioned, certain forms of knowledge are still likely to be viewed as inferior or even damaging. Some countries are developing an integrated and territorially focused mental health care system, gradually moving away from the asylum-based and institutional model (Patel et al., 2018).

Some studies have shown that the culture of biomedicine (Keusch et al., 2006; Kleinman & Benson 2006; Lee et al., 2005), attitudes and representations held by health professionals can also play an important role in maintaining stigmatizing and stereotyping practices (Corrigan, 2006; McLaren et al., 2023; Morant, 1998; Ringer & Holen, 2016; Schulze, 2007), which need to be targeted in anti-stigma campaigns. These aspects reiterate that people living the experience of

mental ill-health are given few opportunities to present and discuss their own knowledge, therefore feeling stigmatized and restricted in the degree to which they can become active participants in their healthcare pathway, what can impact in health-seeking (McLaren et al., 2023). For these reasons, the present research aimed to bring the perspectives of diagnosed people to the public health debate.

Caroline Howarth et al. (2004) points out that, given the power structures within the mental health system, the professionals' definitions of mental illness are likely to be seen as correct and those regarded by diagnosed people tend to be less valued or overlooked. Nonetheless, also emphasise that, when people's perspectives, beliefs and experiences are disregarded, it can affect the professional-patient relationship, especially the relations of trust, disclosure, effective communication and treatment.

Studies regarding mental health service users' perspective have shown that they were seeking for health care relationships in which they experience trust, genuine interest, empathy, attentive listening, flexibility, autonomy, understanding and acceptance, respect, compassion and effective communication (Buszewicz et al., 2006; Epstein, 2006; Horgan et al., 2021; Rogers et al., 2001). Relational practice was identified as the central overarching approach to support people with complex emotional needs, which involves care delivered in a non-stigmatising and individualised way planned collaboratively with service users to ensure their multiple needs are addressed in their healthcare journey (Jørgensen et al., 2020; Trevillion et al., 2022), what is aligned with the supported decision-making perspective. Although these aspects were highly valued, these practices were not experienced as commonly by users as they would like to (Jørgensen et al., 2021; Ringer & Holen, 2016; Rose, 2001). Other negative experiences with mental health services were related to feeling misunderstood and judged by health professionals, as well as when their opinions were overlooked (Epstein, 2006; Trevillion et al., 2022). Users also criticized the paternalistic and controlling practices (Jørgensen et al., 2021), stigmatising interventions, lack of effective support, service fragmentation (Trevillion et al., 2022), the short time of consultation and when the healthcare was more based on medication rather than on counselling or psychological support (Graham et al., 2014; Rogers et al., 2001). These findings show the importance of considering the individuals' perspective of the mental ill-health process as it influences the recovery process.

## METHODOLOGY

To investigate the perspectives of people diagnosed with a mental disorder in their experiences with health services and to explore how social representations of mental health shaped participants' lives, we designed a qualitative phenomenological approach. According to Patrik Aspers (2004), phenomenology is the field that studies complex phenomena based on people's subjective experiences and interpretation of the social world to understand meaning construction based on an inter-subjective level. Phenomenology aims to study human phenomena in the way it is experienced and to understand how people construct meanings.

Ethical approval to conduct the study was not required according to the Spanish Biomedical Research Law (BOE 14/2007-July 3<sup>rd</sup>) and the Organic Law 15/1999 on Protection of Personal Data, which were read and carefully followed. Two ethical committees from Barcelona (Universitat de Barcelona and Universitat Autònoma de Barcelona) were consulted and both gave the same information: for this type of research, it was not mandatory to be assessed by an Ethical Committee, since the procedures corresponded to voluntary interviews with association members. Written and consent informed for participation in the study was sought and granted from all participants. We used pseudonyms to protect their identify.

The study was carried out in the Socio-Cultural Association Radio Nikosia<sup>1</sup> (SCARN) in Barcelona, Spain, a collective formed mostly by people who were diagnosed with a mental illness. SCARN is a non-profit civil association, self-managed by its participants, aiming to generate an independent communication channel to deconstruct the stigma related to mental health. Activities developed in Nikosia take place in a free radio station (Contrabanda-FM) and in a leisure centre (Convent de Sant Agustí). The research project was presented and approved by the Nikosian Assembly<sup>2</sup>. The setting was chosen due to its potential to introduce critical views from its members, which requires the results to be situated with this specificity that does not seek to represent general experiences of people living with mental health problems.

The data sources include semi-structured in-depth interviews. The interviewees were recruited during the participation in the Association' activities. Twelve Nikosian members were invited and all of them accepted to be interviewed.

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<sup>1</sup> More information is available at: <http://radionikosia.org> and <http://radionikosia.blogspot.com/>

<sup>2</sup> Nikosia Assembly is a weekly meeting open and democratic to the participation of all members to decide issues related to the association, its management and activities.

The inclusion criteria were: had been diagnosed with a mental disorder, had been through health services, be older than 18-years-old and in emotional conditions to be interviewed, and accept to participate signing the consent informed. Purposeful sampling was chosen in attempt to achieve a diversity of experiences in terms of diagnosis.

All the interviewees were Spanish from Catalonia; they were not working at the time of the interview and were receiving benefit, although ten of them had been previously employed. The economic level varied greatly, depending on the family income and how they share it. The period of participation in Nikosia ranged from at least six months to twelve years. The interviewees have been through mental health services at least within the last twelve years, and one participant had lived for forty years in a psychiatric hospital. Most of them considered themselves in a stable phase of the mental ill-health and a few perceived themselves as recovered. Participants received the following diagnoses of mental disorder: schizophrenia (5), bipolar disorder (3), depression (2), and borderline personality disorder (2).

The instrument used to collect information was a semi-structured in-depth interview guide that was piloted once in order to adjust its format and content. The interview guide begins with open questions about the first experience of mental distress, continuing the process of establishing the diagnosis and how this experience impacted in their personal trajectory. Each interview lasted between 45 and 140 minutes (mean of 92 minutes) and in a total of approximately 20 hours added up. All interviews were recorded in audio, with participants' consent, fully transcribed by the researcher and were coded using NVivo software. The categories were derived inductively and obtained gradually from the data (Groenewald, 2004) in an inclusive approach to reflect as many of the nuances in the data as possible (Pope et al., 2000). The analysis of the encoded interviews was based on qualitative content analysis (CA) principles, which focuses on the characteristics of language as communication with attention to the content and contextual meaning of the text. An explicative content analysis was chosen to clarify diffuse, ambiguous, or contradictory passages by involving context material in the analysis, explaining the particular meanings attributed by participants (Flick, 2009).

## **RESULTS**

All of the participants had experiences with some form of mental health services, usually over long periods of time. Among these services were psychiatric hospitals, day hospitals, community rehabilitation services, mental health centres (outpatient), primary care services (GPs), supported accommodation, pro-

tected job reinsertion, and also user-led services (social club). Mental health services were experienced either as empowering and helping users to recover or, were considered as having a negative impact on their lives. Sometimes, there was a mixture of both. The study findings regarding the experiences with health services from the perspective of people diagnosed with mental ill-health were organized into themes considering the institutions and practices, and the relationship established with professionals. These results will be presented unravelling the ways social representations mediated the narrated experiences.

### **Mental Health Services & Practices**

All of the interviewees had experienced at least two psychiatric hospitalizations, and most of the narratives expressed dissatisfaction regarding this type of treatment. The psychiatric hospital was described as an extreme example of a negative experience; being compared to prisons, either in the sense that they could have punitive and coercive practices, the doors being locked, or inappropriate care lacking therapeutic approaches. Participants who had been through psychiatric hospitalization during recent years and those who had been through it several decades ago had roughly similar perceptions, even after more than thirty years of psychiatric reform.

I didn't find any help in the psychiatric hospitalization. The day was very long and we were not allowed to go out. If you didn't follow the restricted rules, you wouldn't be able to receive visits or calls, everything was controlled. It was like a prison; they enforced the rules. The listening part was lost. (Max, personal interview, January 2015)

Most of the participants questioned how they could have gone through recovery in a psychiatric hospitalization where freedom was limited, and the treatment offered was almost exclusively based on high doses of medication. The participants reported being sedated to the point where they had to lay down, having to sleep for days, which they did not consider as the proper type of care to enable recovery. The majority of the participants mentioned that they had been through authoritative situations, becoming voiceless and powerless, losing the autonomy and the right to decide about their own treatment, especially in the psychiatric hospitalizations, where the hierarchical knowledge system is stronger, in which the views of diagnosed people were overlooked, shaping the experiences and their self-perception as if their knowledge was worthless.

Psychiatric hospitals don't cure people. Once you get in, you're condemned to be over-medicated and shut in all the time. There is no freedom. There is always a hierarchy in which the patient is voiceless and can't make their own decisions. Fortunately, we are free and autonomous human beings, which is very important for growing as an individual. However, in



the psychiatric hospital you don't have this, as it is an authoritative entity.  
(Pablo, personal interview, March 2015)

Some participants narrated that, after experiencing the treatment and conditions offered in the psychiatric hospitalization, they realized that it would be better to follow the rules and what was expected from them to be discharged as soon as possible. This position can be seen as a way to cope with the hierarchical and authoritative institution, in which participants engaged to understand the possibilities to stay there the least possible amount of time, looking for resistance strategies to avoid being hospitalized, while learning how to navigate the psychiatric setting.

Luis, who lived for forty years in a psychiatric hospital, mentioned that, although he got used to living there and making good friends, he disliked the lack of freedom to go out and to choose his own treatments, as well as the institutional environment due to the lack of care, poor hygienic conditions and the punitive mechanisms, such as leaving the interns naked in the inner courtyard and the use of forced injections as a punishment for breaking the rules or simply to show the authority and hierarchy. He also reported receiving electroshocks three times per week without being able to choose whether or not he wanted them as treatment. However, two other participants went through this type of treatment because it was authorized by their family members. Even though they were adults, they had not been asked. In both situations, they were denied the possibility to express their opinion and exert the right to choose, in which the dominant expert representation prevails as well as the family decision became more important. The majority of the participants had also experienced the use of coercive and violent measures in psychiatric hospitalization, such as chemical and physical restraint; most of them narrated scenes in which they were tied to the bed, feeling humiliated.

We were over-medicated, almost like zombies. I just wanted to be in bed, but they forced me to get up, without offering any care. There were violent scenes that I didn't want to see. I remembered when they caught a boy, he was screaming a lot, but I didn't know what would be worse because if he was released, they would have injected him. The violence must be left out. (Amy, personal interview, February 2015)

These coercive and punitive mechanisms were often questioned in the narrated experiences, as the participants mentioned that they would prefer to be respected and listened to in a more humane approach instead of being injected or tied up. Nonetheless, the psychiatric hospitalization was evaluated as useful in a few situations, when participants mentioned the need of rest and protection. However, even in these cases, they did not feel this experience helped

them to recover as it did not provide the tools to deal with the suffering. The hospitalization, in some cases, was seen as a revolving door because when discharged some of the participants mentioned going back to the same place where the suffering was generated or worsened. These interviewees questioned the treatment because usually family was not included, even when there were significant conflicts.

The authoritative and hierarchical model based on the use of protocols was also described by some participants in extra-hospital services. The interviewees who were living in supported accommodation<sup>3</sup> mentioned the control practices in this place, even for those who were living autonomously were submitted to strict protocols in which their rooms were checked on a weekly basis, in which the health professional advices should be followed by the diagnosed people to keep living there.

Participants experienced that the activities and practices offered by the community mental health centres were very controlled and childlike, based on simple tasks that did not encourage them to think and to develop themselves. In addition, the interviewees mentioned that there was no possibility to choose in which activities they would like to participate in as they were enrolled by health professionals.

The workshops of the mental health community centre were far too controlled. They entertain people there; they don't encourage people to think. It's good when you go to a workshop where activities make you think and change things in your life, something that makes sense for you. We can't accept that they treat us like children, just doing simple things, infantilizing us. I think we should be treated as valid citizens with responsibilities and duties. There is a lot of hierarchy within the world of mental health and we are always considered as sick or poor things (Juan, personal interview, January 2015).

The over-medicalisation was also strongly criticised as most of the participants described that people were sedated and seemed deteriorated, sleeping and drooling during the community mental health centre activities due to the medicines' effect. Some participants also questioned the 'trivialization of prescrib-

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<sup>3</sup> The supported accommodation (*llar amb support* in Catalan and *piso asistido* in Spanish) is a house or an apartment that allows people with mental disorders to have an ongoing support to live independently. Each person has their own room and there are shared common areas. The support offered depends on the people's autonomy and capability to live on their own. The people who live in this accommodation follow their healthcare treatment in the mental health centre or in the day centre (depending on which institution is managing the accommodation). There are also residences for people who need more support, where activities are offered and the meals are provided.

ing psychotropic drugs' (Enric) for daily issues and the indiscriminate use of these drugs with children without a rigorous evaluation, as it was experienced by two interviewees. Nonetheless, the participants did not deny medication as a solution, but some of them questioned it as the central treatment offered and sometimes the only one. However, a few interviewees mentioned the positive effects of medication when they found an appropriate one to relief the symptoms.

The aspects recognized as positive by the participants in the community mental health centre were the possibility to socialize with others, to make friends and support themselves. Participants mentioned having a positive outcome from group and individual consultations when they felt listened to and took part in the supported-decision making about their therapeutic journey. In addition, the workshops like music-therapy, emotional expression and physical activities were experienced as positive.

Some interviewees spoke of a one-track discourse<sup>4</sup>, when they experienced health practices based solely on one type of knowledge in unidirectional way: the biomedical - that considers the disease as a deregulation of neurotransmitters. For some participants, this model responded adequately to their needs. Nonetheless, others stated that the centrality of biomedical representations became a reductionist model when disregarding other needs and perspectives; a few interviewees claimed for the co-existence of different theories and practices, encompassing the complexity of human beings in which the variety of representations are taken into account - including the health service users' perspectives and experiences. Moreover, a few participants mentioned that, when questioning the treatment offered, often this attitude was considered as if they did not have awareness on the disease, once again, de-legitimizing their representations.

It is the usual monologue discursive: 'Your brain chemistry doesn't work well and what you need is a regulator, which is pills'. There are no alternative messages of the need to create healthy families in which people can develop themselves as individuals. They don't think that there are authoritarian tendencies that generate *mentally ill* people, such as a psychiatric hospital, where we're suppressed, overmedicated and noiseless. My experiences with psychiatrists have been a bit terrible, because the only option they offered me was pills, which didn't help me. I always believed in the word mediation. (Juan, personal interview, January 2015)

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<sup>4</sup> The literal translation to English would be '*monologue discourse*' (monologo discursivo in Spanish), but it was adapted to a more understandable expression in English.

Moreover, some of the participants mentioned that they were used to describing themselves with a sickness discourse, in the sense that they had incorporated the biomedical representations. They exemplified this by situations where they presented themselves using the diagnostic category, as well as by talking about their feelings through symptoms named by health professionals.

That was when I started having problems with obsessions. I became obsessed with one person and then had delusions of grandeur, but I tried to hide everything. Then I explained my paranoia and my megalomaniac obsessions (Amy, personal interview, February 2015).

In the quote above, the participant incorporated the expert representations to describe her feelings. Probably, before her experience through the mental health services, she would not have been able to describe her experience with the words used in this quotation, what have been similarly experienced by other participants. This phenomenon can be understood as the internalization of the biomedical discourse, as these representations are socially accepted and valued, which led toward the expropriation of their own semantics (language) on how they would have expressed their experiences before going through mental health services. However, there were a few interviewees who mentioned having experienced the de-construction of the internalized sickness discourse in the relationship with health professionals. These experiences were more common for people who were attending psychotherapy and for those who had been participating in Nikosia Association for several years.

On the first day she [psychoanalyst] asked me the reason for coming and I answered: 'I have a borderline personality, I feel misunderstood and that I am worthless, I self-harm...'. Then she asked me: 'can you tell me about yourself without using descriptions from a medical book? What is hurting you?' I didn't know what to say! I went home thinking about it... no one had asked me that before. (Martina, personal interview, January 2015)

### **Relationship with Health Professionals**

The majority of the participants had both positive and negative experiences with health professionals; they emphasised that the relationship depended more on the person and the connection they had with them. The interviewees described that this situation was a kind of luck; the healthcare provision in Spain is based on territory, meaning that one has access to a specific health service provider depending on the address of residence. Therefore, the person can be lucky to meet a health professional who understands and listens to them. Another positive aspect mentioned was when the health professionals focused not only on the disease, but on the person's life in a comprehensive approach.

The doctor who I currently have is really nice; she has helped and supported me a lot. She does not talk about the disease; she asks me about life what I really like. (Mafalda, personal interview, January 2014)

The central aspect narrated by participants having had a positive experience with health practices was related to being listened to, cared for and understood by health professionals in an empathetic and horizontal relationship. They mentioned the importance of being respected for their time and needs, as well as feeling valued and not judged. All interviewees highlighted how important it was for them when their views were taken into consideration in a supported decision-making approach, occurring only in a few situations. After living a disempowering process of being subjected to the *mentally ill* label in a stigmatising society, it seems that experiencing a positive relationship with health professionals where users' strengths and perspectives were emphasised, had enabled them to make decisions and reclaim the control of their own lives, contributing to a more positive self-perception/confidence.

My childhood psychiatrist helped me a lot. I think we connected a lot and she got fond of me. She read my diary and spoke about it without dramatizing, communicating corresponding to my age, giving the importance needed, without making me suffer. She gave me space to be a child, covering the emotional part that I didn't have. She understood me and didn't judge me. I never felt she decided for me, consulting me for everything, respecting my time. (Martina, personal interview, January 2015)

Although all of the participants had significant appreciation when horizontal relationships were established with health professionals in a supported decision-making approach and in a joint meaning-making process, these practices were not experienced as commonly as expected. Most of the interviewees narrated experiences when health professionals authoritatively decided what would supposedly be better for them, instead of asking and taking their opinion into account. A few participants considered this attitude as a form of superimposing the professionals' representations and ignoring some of their life possibilities, such as being a parent, as well as having a life with a partner, because of the mental-ill label. These attitudes were experienced by some of the participants as if the biomedical representations have labelled them as unable to deal with potentially stressful situations, wiping out their desires and some life possibilities.

There are many professionals who still think that a diagnosed person can't have a partner, even less so if the other is also diagnosed. They are denying a desire! When I was diagnosed, they told me that I may not have children. Often, they said: 'this will be better for you'. They rarely asked me: 'What do you want? What do you think?' In the last hospitalization, they

took my books about mental health away and told me to leave everything related to this topic, but all of this helped make sense in my life. I felt that I was completely defeated... everything that gave me life was denied. (Martina, personal interview, January 2014)

In this experience narrated by Martina, it seemed that the expert representations were overvalued in regard to what would be better for her, disregarding a significant element that made sense in her life: becoming an activist. Once again, the hegemonic expert representation prevails and the experiences of diagnosed people tended to be overlooked. Another barrier identified by a few interviewees was the stigmatizing attitudes expressed by health professionals towards people with a mental health diagnosis. In this way, the diagnosis was experienced as a label that marked the participants on their pathway through the health system, even when seeking help for another reason.

I felt stigmatized by professionals. When you look for help because you have a migraine, they write down 'psychiatric patient' and then ask you: 'are you feeling nervous?' And I thought: 'no, my head can hurt just like yours'. So please, treat me like a person who has a migraine and not as somebody who is mentally ill. (Ana, personal interview, February 2015)

On the other hand, all of the participants who had some experience with the ISP<sup>5</sup> (Individualized Service Plan) recognized this approach as a very positive in their recovery, mentioned aspects of receiving closer support outside the institutional structure, which enabled a more comprehensive approach. The possibility of calling the ISP professional at any working hour was also appreciated by the participants.

The fact that you don't see the health professional [ISP] in an office, in an institution, that they don't wear a white coat... and you can talk about everything, they make you laugh and you feel a closer support. In my case, I felt less sick, as I went around with someone who is helping me to overcome the crisis and to find my own way. He is treating me like the rest of the team, but in a different way from the clinical setting. It makes a difference to talk with a professional whilst walking along. It's more humane, accompanying someone to know their reality, to get to know their problems. (Noa, personal interview, March 2014)

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<sup>5</sup> The Individualized Service Plan (ISP) is an organizational method using an active process to manage mental illness inside the community, especially in acute situations or after a discharge. The main objective of the ISP is to adapt healthcare and social services to the specific needs of each patient and to keep them as much as possible in their own environment, to strengthen the continuity of care. It consists in a health professional (it could be a psychologist, social worker, socio educator, etc.) accompanying someone outside the clinic. The ISP belongs to a mental health centre team and participates in the meetings and case discussions. It is similar to the therapeutic accompanying.

Other elements highlighted by the participants as relevant in regard to health professionals were the use of a theoretical approach compatible with users and the importance of time and frequency of the consultations which enable a more in-depth understanding of participants' lives. Most of the participants narrated that they did not receive enough information from health professionals about their situation, which generated anxiety. To deal with that, they took the initiative to seek out information on their own by reading books and leaflets on mental health to have a better understanding of their situation and how to make progress.

## **DISCUSSION**

Regarding the experiences with the mental health services though the perspective of diagnosed people, the participants narrated situations marked by hierarchies, power structures and controlling practices, similarly to Caroline Howarth et al. (2004), and Kim Jørgensen et al. (2020, 2021) findings. Moreover, the centrality of biomedical representation with unidirectional approach was questioned by participants, as their perspectives were overlooked or less valued. These findings are similar to other studies (Graham et al., 2014; Ringer & Holen, 2016; Rodríguez, 2004; Trevillion et al., 2022), where the majority of diagnosed people did not feel involved in supported decision-making about their healthcare journey, criticizing the lack of information and treatment being heavily based on medication. Among European countries, Spain has one of highest rates of psychotropic consumption, showing a prevalence of 13.9% (Maestre-Miquel et al., 2021).

The legitimacy of the expert representations had shaped the participants' experiences and identities, as they felt voiceless and powerless. In this study, participants felt that some of their life possibilities were ignored/denied because of the mentally ill label, such as being a parent as well as having a life with a partner. Another effect was the incorporation of expert representations to describe their own experience, sometimes assuming the sickness discourse. It seemed that, when the biomedical representation was dominant, the people with a mental ill-health tended to be positioned as unable to participate and decide about their own health.

Another finding that drew attention was the fact that interviewees who had been through psychiatric hospitalization during recent years and those who had been through it several decades ago had roughly similar perceptions; this suggests that the health-related practices have not been changed significantly within psychiatric hospitalization. Another observation highlighted from this study was the criticism of the activities provided by community mental health

centres that were infantile; participants felt that their capability was belittled, as if they were incapable of dealing with challenging tasks; that had also shaped participants' self-perception. Criticism related to stigmatizing attitudes held by some health professionals was found in other studies (McLaren et al., 2023; Ringer & Holen, 2016).

The participants positively valued the experiences with health professionals when they felt supported, listened to and cared for, especially when they had their perspectives taken into consideration in a supported decision-making approach, having their autonomy respected and encouraged, similarly to other studies (Epstein, 2006; Graham et al., 2014; Horgan et al., 2021; Jørgensen et al., 2021; Trevillion et al., 2022); however, these expectations were less experienced than expected.

The sample for this study was limited to members of the Nikosia Association, in which participants are more likely to be critical compared to diagnosed people who did not participate in other types of associations. In this sense, participants are not very representative of the general population living with a mental illness, which is the main limitation of this research. Despite that, this setting presents a singular and interesting perspective, in which we can learn from Nikosian members experience. Although qualitative studies allow investigators to retain the holistic and meaningful characteristics of real-life events, it is not its purpose to provide scientific generalization. Findings should be considered context and cultural-dependent.

## CONCLUSION

This study has investigated perspectives of people diagnosed with a mental disorder in their experiences with health services and analysed how social representations shaped their lives. Research participants were members from Radio Nikosia Association in Barcelona, Spain. The study findings aligned with results from previous investigations in which individuals with a mental health diagnosis are rarely involved in their own healthcare, having their views overlooked. The experiences marked by the biomedical representations in unidirectional approach tended to position the diagnosed individuals as incapable of being the protagonists of their own lives and to decide about their healthcare pathway, which have shaped their self-perception/confidence and identities—feeling voiceless and powerless.

The central aspect identified by participants as positive was related to being listened to, cared for and understood by health professionals in an empathetic and horizontal relationship. The possibility to socialize and to develop mutual



support was also recognised as constructive in mental health services, as well as being respected, feeling valued and not judged. Experiencing a positive relationship with health professionals where users' strengths and perspectives were taken into consideration had enabled them to make decisions, contributing to a more positive self-perception, especially when feeling supported and encouraged to lead their own lives. These experiences facilitate to contest derogatory representations and to build more affirmative identities.

These varied perspectives should be taken into consideration in order to improve the mental healthcare provision in a more comprehensive, effective and sensitive approach to be aligned with people' lives and needs. Additionally, individuals with a mental ill-health should be actively involved in the evaluation and planning of health services and policies related to mental health, as well as having their views considered in the professional trainings and in the development of anti-stigma campaigns.

The topic of focus in this study—perspectives of people diagnosed with a mental disorder in their experiences with health services—has not been sufficiently tackled by researchers yet. Therefore, it would be highly recommendable to develop more research with this focus, to delve more deeply the understanding of the phenomenon. In further studies, the sample can include not only association members, to contribute with a broader picture of the experience of living with a mental ill-health. Participatory research can be an interesting methodology in which participants are actively involved in data elicitation and analysis of their reality to build collective knowledge.

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#### LIANA CRISTINA DALLA VECCHIA PEREIRA

PhD in Human Sciences (UFSC). Department of Psychology, University professor at the Federal University of Santa Catarina, Brazil.

[lianadvp@gmail.com](mailto:lianadvp@gmail.com)

<https://orcid.org/0000-0002-4200-2464>

#### CARLOS ALBERTO SEVERO GARCIA-JR

PhD in Human Sciences (UFSC). Department of Health Sciences, University professor at the Federal University of Santa Catarina, Brazil.

[carlos.garcia.junior@ufsc.br](mailto:carlos.garcia.junior@ufsc.br)

<https://orcid.org/0000-0003-3367-4151>

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