“It pulls you down, but you need it to access the benefits”: the double-edged sword of mental illness diagnosis

“Eso te machaca, pero lo necesitas para acceder a los beneficios”: la espada de doble filo del diagnóstico de enfermedad mental

“Isso te esmaga, mas você precisa para acessar aos benefícios”: a faca de dois gumes do diagnóstico de doença mental

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Abstract

Mental ill-health is rife in all corners of the world. Mental illness diagnosis simultaneously names the problem and labels a person. Taking a social representations perspective, this phenomenological study explores how 12 people living with a mental disorder in Barcelona, Spain, experienced their diagnosis. They experienced having to process what this “diagnosis for life” meant for their sense of self. Immediate encounters of stereotyping and changes in their social relations, reinforced their experience of being “stigmatized for life” and seen as “mentally ill all the time”. Participants did however also note that the diagnosis helped them make sense of the past and the future, including enabling access to specific benefits, which supported their recovery and helped them make ends meet – highlighting the ambivalence of mental illness diagnosis. This study highlights the need to consider the social context and patients’ narrated experiences of diagnosis centre stage.

Keywords: mental health; mental diseases; psychological diagnosis; psychiatric diagnosis; social representation; stigmatization; Spain

Resumen

Los problemas de salud mental son comunes en todos los rincones del mundo. El diagnóstico de enfermedad mental simultáneamente nombra el problema y etiqueta a una persona. Desde la perspectiva de las representaciones sociales, este estudio fenomenológico explora cómo 12 personas que viven con un trastorno mental en Barcelona, España, experimentaron su diagnóstico. Ellos tuvieron que lidiar con lo que significaba el “diagnóstico para toda la vida” en el sentido de identidad. Los encuentros mediados por estereotipos y cambios en las relaciones sociales reforzaron la experiencia de ser “estigmatizados de por vida” y vistos como “enfermos mentales todo el tiempo”. Sin embargo, los participantes también perciben que el diagnóstico les ayudó a comprender el pasado y futuro, incluyendo el acceso a beneficios específicos que contribuyó a su recuperación y a sobrevivir económicamente, destacando la ambivalencia del diagnóstico de enfermedad mental. Este estudio destaca la necesidad de considerar el contexto social y las experiencias de los pacientes.

Palabras clave: salud mental; enfermedades mentales; diagnóstico psicológico; diagnóstico psiquiátrico; representación social; estigmatización; España

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Resumo
Os problemas de saúde mental são comuns em todos os cantos do mundo. O diagnóstico de doença mental simultaneamente nomeia o problema e rotula uma pessoa. Na perspectiva das representações sociais, este estudo fenomenológico explora como 12 pessoas que vivem com um transtorno mental em Barcelona, Espanha, experienciaram seu diagnóstico. Eles tiveram que lidar com o que o “diagnóstico para a vida” significava no senso de identidade. Os encontros mediados por estereótipos e mudanças nas relações sociais reforçaram a experiência de serem “estigmatizados para a vida” e vistos como “doentes mentais o tempo todo”. Contudo, os participantes também percebem que o diagnóstico os ajudou a entender o passado e o futuro, incluindo o acesso a benefícios específicos que contribuíram na sua recuperação e para sobreviver economicamente - destacando a ambivalência do diagnóstico de doença mental. Este estudo destaca a necessidade de considerar o contexto social e as experiências dos pacientes.

Palavras-chave: saúde mental; doenças mentais; diagnóstico psicológico; diagnóstico psiquiátrico; representação social; estigmatização; Espanha

Mental ill-health is rife in all corners of the world, affecting every age group and community (World Health Organization [WHO], 2010). The field of mental health has been marked by social exclusion, stigmatization, discrimination and the violation of human rights. People diagnosed with a mental disorder often have their views de-legitimized and are denied civil and political rights, limiting their personal liberty in many life aspects, such as to participate effectively and fully in public life, as well as exercising their legal capacity on issues that can affect them, including their treatment and care (WHO, 2013). While much has been done to explore public and professional perception of mental health, the views of people diagnosed with a mental illness is often limited to their perceptions of the illness, their lived experiences of stigma and its impact on their help-seeking behaviours (Epstein, 2006; Min, 2019; Mjosunda et al., 2015). Studies conducted with people diagnosed with mental illness show that stereotyping, prejudice and discrimination prevail in their everyday life (Barbosa et al., 2018; Choudhry et al., 2016; Conner et al., 2011), experiences which are heightened amongst people with severe mental disorders (Ye et al., 2016). Lack of knowledge and fear of stigma continue to act as barriers to accessing healthcare (Corrigan et al., 2014; Jansen et al., 2015; Schomerus & Angermeyer, 2008), especially when being labelled as mentally-ill is associated with being unpredictable or blameworthy (Mojtabai, 2010). This article explores further the effect of being diagnosed, or labelled, with a mental illness on people’s lives, by exploring how social representations of mental illness and stigma permeate the everyday lives of people in Barcelona, Spain, following a mental illness diagnosis.

Mental illness diagnosis: social representations and stigma
According to 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. These codes, or representations, permeate social relationships, cultural practices and power relations. Individuals who experience a mental disorder may have to confront derogatory codes that disrupt their own notions of health-illness and self, which can have profound stigmatizing consequences for the individuals’ identities (Howarth et al. 2004). To study how social constructs shaped the diagnosis experience, the study thus take inspiration from the social representations of mental illness and stigma literature.

Several studies have identified the consistency of social representations of mental illness as historically grounded and associated with themes such as otherness, strangeness, fear, unpredictability, dangerousness and threat, as well as linked with negative views of deviance and abnormality (Barbosa et al., 2018; Choudhry et al., 2016; Dixit, 2005; Foster, 2001; Jodelet, 1991; Tassone-Monchicourt et al., 2010). Even in situations of apparent integration, the use of subtle but powerful ways of excluding the mentally-ill persists (Morant, 1995). In an analytical study of mental illness representations in four Spanish newspapers, Bueno Abad and Mestre Luján (2005) revealed its negative categorization associated to irrational and unpredictable behaviour, lack of control and social danger; contents varied from scientific thought and the judicialization of aggression. Similarly, Cabruja (1988) and Ayestarán and Páez (1986) found that in the Spanish context, lay population allocated a significantly marked sense of illness and abnormality for behaviours related to mental disorder, permeated by depreciative representations as diagnosed people were considered as irrational, unpredictable, irresponsible, different, threatening, dangerous, special for coping with problems and causes of humiliation for the family.

When considering the effects of a psychiatric diagnosis, Rössler (2013) points out the stigmatizing impact to be seen as mentally-ill, a label associated with derogative stereotypes, even though it provides the access of social benefits and health assistance. Similarly, Pitt et al. (2009) found that diagnosis of psychosis involved both positive and negative elements as it can be a mean of access treatment by naming the problem as well as a cause of disempowerment by labelling the person. Stigma related to mental illness was also experienced by diagnosed people through negative beliefs and attitudes, social exclusion, subjected to contemptuous treatment, requirement of medical endorsements for employment, among other aspects (Ong et al., 2020). A study conducted by Rose and Graham (2010) revealed that mental illness diagnosis had marked a formal status of psychiatric patient followed by stigma and unwanted label in the majority of cases, as consumers felt reduced to the disease. In this sense, Corrigan (2007) highlights that stigma can exacerbate significantly the lived experience of mental illness by the prejudice and stereotypes that result from misconceptions with a great impact on the sense of self that can be internalized into self-stigma. Stigmas of mental disorder seem to be widely endorsed by the general public and even among well-trained professionals in Western nations, what mediates sanction and discriminatory attitudes against diagnosed people subscribed to negative stereotypes (Corrigan & Watson, 2002). General practitioners who worked more closely with the mental health team had a better perception of mental illness needs and less stigmatization towards diagnosed people (Castillejos Anguiano et al., 2019). Overall, the position of people labelled as mentally ill within their relationships is mediated by a complex web of factors and cultural constructs which moderate social practices based on different knowledge systems, a relevant scope to be analysed through the experience lived by diagnosed individuals.
Methodology

To explore how people living with a mental disorder experienced their diagnosis and to discuss how stigma and social constructs mediated their experiences, a qualitative phenomenological approach was designed. According to Aspers (2004), phenomenology is the field that study complex phenomenon based on people’s subjective experiences and interpretation of the social world to understand meaning construction based on an intersubjective level. Ethical approval to conduct the study was not required according to the Spanish Biomedical Research Law (BOE 14/2007-July 3rd) and the Organic Law 15/1999 on Protection of Personal Data, which were read and carefully followed. Two ethical committees from Barcelona (Universidad de Barcelona and Universidad Autónoma 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. Pseudonyms were used to protect their identity.

Study location and participants

The study was carried out in the Socio-Cultural Association Radio Nikosia¹ (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.² 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. The first contact with Nikosia was in an internship during the residency in family and community health, what facilitated the research approach. Twelve Nikosian members were invited and all of them accepted to be interviewed. 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, gender and age distribution, according to characteristics presented in table 1.

¹ More information is available at: http://radionikosia.org and http://radionikosia.blogspot.com/
² 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 double-edged sword of mental illness diagnosis

Table 1
**Demographic characteristics of participants**

<table>
<thead>
<tr>
<th>Item</th>
<th>Male ($N = 5$)</th>
<th>Female ($N = 7$)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age (years)</strong></td>
<td></td>
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</tr>
<tr>
<td>31-40</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>41-50</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>51-60</td>
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<td>1</td>
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<tr>
<td>61-70</td>
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<tr>
<td><strong>Education</strong></td>
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</tr>
<tr>
<td>Elementary school</td>
<td>1</td>
<td>2</td>
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<tr>
<td>Secondary or Professional training</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Uncompleted undergraduate</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Uncompleted PhD</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td><strong>Living conditions</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>With the family</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Alone or sharing a flat</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Supported accommodation</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Residence</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td><strong>Marital status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>With a partner</td>
<td>1</td>
<td>3</td>
</tr>
</tbody>
</table>

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), bipolarity (3), depression (2), and borderline personality disorder (2).

**Data collection and analysis**

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).

Findings

The study findings regarding the experiences of mental illness diagnosis and its impact in participants’ lives were divided into four main themes: a) Process of establishing the diagnosis for life; b) Stereotype and taboo in the society: stigmatized for life; c) Change in social relations: seen as mentally ill all the time; d) Ambivalence of the diagnosis: the double-edged sword. These results will be presented unravelling the ways social representations and stigmas mediated the lived experience of being diagnosed.

Process of establishing the diagnosis for life

Based on the narrated experiences, establishing the diagnosis was rarely made in a shared decision-making process. Most of the participants were diagnosed after the first psychiatric hospitalization and, in general, the majority did not receive clear information about the diagnosis. On one hand, when the interviewees had the opportunity to participate in this process, they mentioned that they were able to have a better comprehension of what had happened to them and to look for appropriate help, feeling a kind of relief in the sense that their suffering has an explanation. On the other hand, in the situations marked by the lack of information, people tended to feel puzzled and anxious due to the prevalent pejorative and negative stereotyping representations of mental health.

They didn’t explain what it was, either. I was puzzled! People have a tendency to associate the schizophrenia with danger, with murder, what is completely wrong, but I didn’t know at that time. Most of the affected people think more about committing suicide than killing. It’s like a silent battle (Elena).

The participant Elena mentioned that she discovered her diagnosis long after it was established, stating that she would prefer to have known sooner: “So then I could control myself not to be aggressive”. However, Elena realized that she was never an aggressive person, so why it would change with the diagnosis? This episode can be understood through social constructs, in which the interviewee tried to comprehend the phenomenon based on the hegemonic representations of mental illness that are often linked to aggressiveness, lack of control and dangerousness. Even though she did not recognize herself with these characteristics, she internalized the prevalent and socially accepted representations, which marked her self-perception. Nonetheless, over the time, Elena had other experiences, which enabled her to contrast the dominant representations and to make sense of her own process.

Participants reported having felt the diagnosis as a verdict, being communicated as a diagnosis for life. This was experienced by most of the interviewees at the time that the diagnosis was established, as if there was no possibility for change or improvement. They emphasised the expression diagnosis for life because it is established as a life-long condition with strong changes in their lives, especially in the way they were seen by the others.

3 All references that could identify participants were anonymized and replaced by pseudonyms.
However, it was also seen by participants as a possibility to find a way to cope with the new condition, revealing the ambivalence experienced.

The diagnosis falls like a ton of bricks, as it was the final verdict (...). When they told me ‘you have this disorder, it’s a disease for life, you’ll take this medication, you may not have children’, and I was only 19 years old. When they explained what it was, I felt some relief, as what happened to me had already been studied. I wasn’t ‘strange’, but this condition existed (...). There are days when you hate your disorder and other days you live with normality. You have to adapt and find your own space (Martina).

Another criticism was the fact that health professionals kept to the biomedical hegemonic perspective giving the same explanation to everybody, overlooking patients’ beliefs and spiritual experiences when making a diagnosis.

When they give you a diagnosis you think about it, even though you don’t believe in it. I was humble to recognize that it could be true as I understand that it’s not normal to hear voices, as much as you believe in mediums or not. They give everyone the same explanation of the dopamine, neurotransmitters... and each case is different. A difference must be made between a spiritual crisis and a mental health crisis (Ana).

**Stereotype and taboo in the society: stigmatized for life**

The repertoire of social representations and knowledge about mental health available in the society was regarded as often incorrect and restricted, which, according to the participants, contributed to stigmatizing and derogatory representations. Some of the participants narrated their worry regarding the erroneous stereotypes conveyed by the media, where mental illness is often associated with aggressiveness and dangerousness, which affected the way they are seen by others, leading the public into strategies of avoidance and discrimination of those labelled as *mentally ill*.

Mental illness is still a taboo in society. Well, there were awareness campaigns and people have the same attitude towards diagnosed people as dangerous, bad people. The media have a pejorative point of view of us, they think that we are troublemakers and it’s not really like this. We didn’t have the opportunity to express how we really are. The psychiatrist is the one who defines how the mentally-ill should be (Juan).

Juan highlighted that representations held by health professionals are considered legitimate to explain the mental health topic, having an important influence on the public understanding of the phenomenon. According to the interviewees, mental health is still a taboo in society and often an avoided subject, hindering people to seek help due to the fear of being rejected and stigmatized if subjected to the *mentally ill* label.

If I meet a neighbour in the mental health centre... I could also meet them at the flu campaign, right? So, why can’t we share a conversation? It is the taboo...
on mental health. There are many people going through it alone because of shame and the fear of rejection, they can’t find a place to talk openly without taboo and shame (Martina).

The participants mentioned that mental health was also a taboo subject in their families and among friends. Some of them had experienced that the diagnosis was put to the forefront in their relations with others. Even when having another illness, the mental illness was always outweighed. All of this entailed a major impact on people’s rights and identity, as the interviewees narrated experiences in which they felt voiceless and without a valued opinion.

The stigma is a burden. Even if you have an important illness, as in my case, but what is highlighted is always the bitter part: the fact that I am mentally ill. The person loses all rights for life when they are diagnosed, you are stigmatized for life (Juan).

Another topic that emerged in the narratives was the weight of self-stigma: when someone had incorporated the socially stigmatized representation. The self-stigma was related to and constructed from the social stigma, corresponding to its internalization, which can impact significantly one’s identity, self-image and self-esteem. It operates through the internal perceptions, beliefs and emotions of the stigmatized person who starts to believe in these negatives stereotyping representations associated with mental illness, similarly to findings from other studies (Corrigan & Watson, 2002; Ritsher & Phelan, 2004). In this sense, it seems that the way they were seen by others was integrated to the self-perception, affecting their identities as it was incorporated, at some point, these public hegemonic understandings that people with a mental illness are worthless or are not capable to deal with every-day tasks. Some of the participants experienced the self-stigma as an internal battle, as some of them did not understand or accept what they were living.

The self-stigma is the worst: ‘I’m ill, I’m worthless, oh poor thing, I can’t do anything...’. This pulls you down (Martina).

I was at war with myself, I was wondering why this had happened to me. I felt angry, so at the beginning when I went to Radio Nikosia I was serious, fed up with life because things hadn’t happened as I would have liked them to (Amy).

**Change in social relations: seen as mentally ill all the time**

The participants narrated that after being diagnosed with a mental illness, they experienced avoidance and discrimination in various settings. Interviewees mentioned that the diagnosis changed the way they were seen and treated by others, having a significant impact on their self-perception. They experienced that the mentally ill label became central in different social settings, as if they were mentally ill all the time. One Nikosian member often brought this question in the radio programme: “I don’t understand why people interact with me as a ‘total mad’ if I only exert as a mad 10 % of my life”. All participants mentioned some experience of rejection, whether by family members, friends, classmates, work colleagues and community members, changing the relations previously established.
My family rejected me even more because of the diagnosis. They kept me away from the family events and I had no contact with my nephews at the first years. I received injections even without needing or asking. My mother didn’t let me do anything, she thought I was incapable, and she controlled me; everything was due to my illness. From then onwards I felt the stigma from others, until I believed that I was worthless (Elena).

When was asked Elena why she was not allowed to stay with her nephews, she told that her family thought that it could be aggressive; she felt very upset and acknowledged that she was never an aggressive or dangerous person. Elena also felt impotent due to the diagnosis, because her voice and opinion were overlooked and her family decided for her, controlling what she could do. These narrated experiences reiterate the dominant representations of mentally-ill label linked to not able to reason or lacking insight.

Nonetheless, only a few participants mentioned a positive impact of the diagnosis in terms of being supported and understood by family, friends and colleagues. Some participants narrated that friendships were kept, although their friends avoided talking about mental health. In this case, they felt that part of their experiences and identity was unwelcome and should be kept as a secret. It not only made it harder to accept and incorporate this experience, but it left people with the feeling that their interactions were superficial and meaningless, as they had to keep this important part of their lives to themselves. Moreover, a case of discrimination was narrated by two participants, in which a neighbour attempted to collect signatures to throw them out from the supported accommodation because the neighbour was afraid that they could be uncontrolled and dangerous for the community. Overall, being subjected to the mentally ill label impacted in all relations leading to, at some point, the exclusion from family events, avoidance on friendship circles, being fired at work, the difficulty in finding a new job, as well as the increase of bullying.

I was recovering and recomposing the puzzle. But what had happened? My old flatmates didn’t want to see me anymore. The places that I had been to, such as school, they didn’t want to give me another opportunity. My colleagues tried everything to make me go on sick leave or to be fired; there were others who accepted me. People can discriminate you when they see the symptoms or if you’re under the influence of strong medication. Only those who love you, such as family, will understand you (Enric).

**Ambivalence of the diagnosis: the double-edged sword**

Interviewees and the majority of Nikosian members narrated the ambivalence and the dual effect of the mental illness diagnosis. On the one hand, it was linked to the social stigma that impacted significantly in their relations. On the other hand, it was associated with the possibility of obtaining treatment, social support and some resources (e.g. benefit, housing, transportation, etc.), so that they could make ends meet and engage in meaningful activities that contributed to recover. Although these were regarded as useful resources, some of the participants questioned the system controversies; even though the mental illness diagnosis was established as a disease for life, it could also result in someone losing their resources if considered recovered, making it difficult to find a job in a society in which stigmatizing and discriminatory representations of mental illness prevail.
From an economic point of view the diagnosis allowed me to breathe, seeing as I had no income; but socially it was hard, due to the stigma and everything that goes with it (...). However I can’t say that I’ve recovered because I need the benefits, I am of a certain age and I have no qualifications that would help me to find work (Juan).

The diagnosis for life is ambivalent as it pulls you down, but you need it to access the benefits. If I didn’t have a diagnosis I would be living despondently with my family and I wouldn’t have recovered without the resources, it’s a double-edged sword (Elena).

Another controversy was the fact that the benefits were given only to people with a high level of disability, evaluated in a court of psychiatrists. Therefore, there were cases experienced by Nikosian members in which they were diagnosed with a mental illness and did not receive any benefit, needing to survive in a stigmatizing society. The dependence on benefits was a constant topic discussed in the Nikosia Association, especially because the members were facing the possibility of losing their resources due to the governmental changes and cost-cutting. Some participants acknowledged that having a diagnosis allowed them economic stability, as well as the possibility of engaging in activities that helped them on the road to recovery, aspects experienced as the positive side of the diagnosis.

If it hadn’t been for the diagnosis, I wouldn’t have been able to spend almost twenty years of my life only for music (...). It doesn’t mean that the diagnosis had helped me, but that it allowed me to live in a way that I couldn’t have lived without it, with devotion to music, to the book that I wrote, and to the radio programme (Max).

The ambivalent effect of the mental illness diagnosis was a common experience amongst our participants. Rössler (2013) and Pitt et al. (2009) had also identified that the diagnosis is a mean for accessing social benefits and healthcare, although it occurs through stigmatizing and disempowerment effects. In this sense, Corrigan (2007) emphasises how stigma exacerbates the experience of mental illness due to prerogative stereotypes with a great impact on the sense of self.

Overall, the process of establishing the diagnosis was rarely done in a shared decision-making process, often made by health professionals, and just communicated to the individuals. Most of the participants perceived the diagnosis as a verdict, feeling stigmatized for life. After being diagnosed, all the participants reported that they had experienced significant changes in social relations feeling avoided, discriminated, and rejected. Only a few participants had more supportive relationships due to the diagnosis. Generally, it seemed that after being diagnosed, participants felt subjected to the mentally ill label, facing derogatory representations that disrupted and shaped their lives and identities. There was a tendency to incorporate, at some point, these negatives construct into participants’ self-perception, internalizing the socio stigma into a self-stigma: belittling themselves and believing they were worthless. The diagnosis ambivalence was identified as central in their experiences due to the social stigmatizing effect that had also enabled the access of specific resources which allowed participants to make ends meet and to recover.
Discussion

When diagnosed, participants felt subjected to the *mentally ill* label, significantly changing the way they were seen and treated by others; they faced derogatory representations as if they were dangerous, unpredictable, and uncontrolled. In addition, they experienced rejection and avoidance in different relations and settings, similarly, to results found in studies considering the lay representations and attitudes towards diagnosed people, mainly related to the diagnosis of schizophrenia (Barbosa et al., 2018; Choudhry et al., 2016; Dixit, 2005; Foster, 2001; Tassone-Monchicourt et al., 2010).

Participants’ perspectives and beliefs rarely were considered in the process of establishing the diagnosis, in which the dominant expert representations prevailed. These experiences shaped participants’ self-perception and identity. At the beginning, the tendency was to accept and incorporate these stigmatizing representations of mental health into their self-perception to some extent, internalizing the social stigma into a self-stigma, feeling worthless. Likewise, findings from Evans-Lacko et al. (2012), Ritsher and Phelan (2004) and Rodríguez (2004) revealed that diagnosed people tended to identify themselves as sick, deranged, unbalanced and confusing, incorporating the derogatory representations into their self-perception, as experienced by all participants of this study with different diagnosis categories—schizophrenia, bipolarity, depression and borderline personality disorder. Moreover, the diagnosis of mental health was often put to the forefront in the participants’ relationships with others, as they felt subjected to the *mentally ill* label as if they were sick all the time, instead of being seen as individuals that, among other aspects, live with an ill-health condition.

The ambiguity constituted a significant element from interviewees’ experience, as the diagnosis of mental illness simultaneously names the problem and labels a person. Participants faced stigmatizing effects that enabled the access of specific resources, which allowed them to make ends meet and to recover. They named this aspect as the double-edged sword of the diagnosis due to its dual effect. Nonetheless, the system controversies were also highlighted because the diagnosis is established as a life-long condition (diagnosis for life), and if someone goes through recovery, they lose the benefits, making it difficult to make ends meet in a discriminatory society. The ambivalent effect constitutes the novelty from the present study that contributes to discuss how social representations mediated the experience of being diagnosed in a stigmatizing and controversial society, issue that can be deepened in future research.

The sample of this study was limited to members of an Association in which participants are more likely to be critical compared to diagnosed people who have not participated in Nikosia. 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 of that, this setting presents a singular and interesting perspective, in which we can learn from Nikosia 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 explored and analysed how mental illness diagnosis was experienced by diagnosed people' to understand how social constructs and stigma impacted in their lives. Research participants were members from Radio Nikosia Association in Barcelona, Spain. The findings have shown that expert’s and public’s representations of mental health have shaped participants’ lives, as they were seen and treated differently after being subjected to the mentally ill label. The changes in social relations were often permeated by stigmatizing and stereotyping representations of mental illness, which were incorporated at some extent into participants’ self-perception, becoming a self-stigma. The study findings aligned with results from previous investigations in which individuals with a mental illness were rarely involved in their own healthcare, having their views overlooked.

The mental illness diagnosis was experienced commonly as ambivalent, as it enabled the access to specific benefits that allowed people to make ends meet and to engage into meaningful activities, which contributed to recover, although it was through the mentally ill label and its stigmatizing effects. This aspect was named as the dual effect and the double-edged sword of the diagnosis, which constitutes the main contribution from this study to the mental health field, as the ambivalence can constitute a significant element experienced with the diagnosis.

The topic of focus in this study –the experiences of mental ill-health and how the social representations of mental health shaped people’ lives, identities and ability to cope with mental illness– 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.

By taking into consideration the diagnosis experience, significant contributions can be made to improve the mental healthcare provision in a more comprehensive, effective and sensitive approach aligned with their lives. Furthermore, we can learn with the recovery process in attempt to identify what make sense in the narrated experiences, such as those promoted by this Association, Radio Nikosia.

References

The double-edged sword of mental illness diagnosis


**How to cite:** Dalla Vecchia Pereira, L. C. & Skovdal, M. (2022). “It pulls you down, but you need it to access the benefits”: the double-edged sword of mental illness diagnosis. *Ciencias Psicológicas, 16*(1), e-2220. https://doi.org/10.22235/cp.v16i1.2220

**Authors’ participation:** a) Conception and design of the work; b) Data acquisition; c) Analysis and interpretation of data; d) Writing of the manuscript; e) Critical review of the manuscript.
L. C. D. V. P. has contributed in a, b, c, d, e; M. S. in a, c, d.

**Scientific editor in charge:** Dra. Cecilia Cracco.