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Activism against stigma: Exploring awareness-raising activities in the healthcare context

Activismo contra el estigma: Exploración de actividades de sensibilización en el contexto sanitario

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Abstract

Stigma suffered by people labelled with mental health diagnoses is something frequent within the healthcare context. Anti-stigma organizations and campaigns have focused their efforts on reducing discrimination in this area. The activist figure is fundamental for people who have experienced this stigma to be the protagonists of this change. Our aim in this study has been to deepen the experience that anti-stigma activists in mental health have when participating in actions to raise awareness in the healthcare context. We carried out a thematic analysis of semi-structured interviews conducted with five activists. We identified two thematic blocks: Stigma and Activism. The Stigma block consists of the themes Prejudice, Discriminatory Behaviours, and Self-Stigma, while the Activism block is composed of the themes Positive Effects, Strategies, and Impact. The present study has allowed us to have deeper knowledge of the subjective experiences of stigma in the healthcare field through the experience of participants in campaigns to combat it, and to understand why activism can be a beneficial strategy to raise awareness among professionals and for the well-being and empowerment of the activists themselves.

Keywords: Activism; Thematic analysis; Social stigma; Mental health

Resumen

El estigma que sufren las personas con diagnósticos de salud mental es algo frecuente dentro del ámbito sanitario. Entidades y campañas de lucha contra el estigma han centrado sus esfuerzos en la disminución de la discriminación en este ámbito. La figura del activista es fundamental para que las propias personas que han experimentado este estigma sean protagonistas de este cambio. Nuestro objetivo en este estudio ha sido profundizar en la experiencia que las y los activistas contra el estigma en salud mental tienen al participar en acciones de sensibilización en el contexto sanitario. Hemos realizado un análisis temático de entrevistas semiestructuradas a cinco activistas. Se han identificado dos bloques temáticos: Estigma y Activismo. El bloque de Estigma consta de los temas Prejuicios, Conductas discriminatorias y Autoestigma, mientras que el bloque de Activismo está compuesto por los temas Efectos positivos, Estrategias e Impacto. El presente estudio nos ha permitido conocer en profundidad las experiencias subjetivas de estigma dentro del ámbito sanitario a través de la experiencia de las personas participantes en campañas para combatirlo y entender por qué el activismo puede ser una estrategia beneficiosa para sensibilizar a los profesionales y para el bienestar y empoderamiento de las y los propios activistas.

Palabras clave: Activismo; Análisis temático; Estigma social; Salud mental

INTRODUCTION

The history of mental health care has been marked by various struggles for the dignity of those affected (Goldman & Morrissey, 1985). In the mid-nineteenth century, the United Kingdom witnessed the initiation of the first political advocacy campaigns, which sought to defend the rights of individuals admitted to psychiatric hospitals (Hervey, 1986). Moving into the twentieth century, movements such as anti-psychiatry, survivor advocacy, consumer groups, and, more recently, first-person perspectives have emerged in our cultural context. These movements questioned the practices of mental health professionals, and many of their demands have been translated into public policies. This has paved the way for processes of psychiatric deinstitutionalization and the implementation of community services, which were introduced in Spain in the eighties (Vázquez-Barquero & García, 1999). As a result of these institutional transformations, albeit not without difficulties, coercive measures and prolonged hospitalizations are starting to decrease. Nevertheless, even today, mental health care is often approached from a paternalistic perspective that may not fully respect the preferences and rights of service users (Sashidharan et al., 2019).

Parallel to the tensions and transformations in mental health care, the concept of stigma was developed. Sociologist Erving Goffman (1963) defined stigma as an "attribute that is deeply discrediting." While Goffman was not the first to discuss stigma, he is recognized as a pioneer in systematizing the concept (Link & Stuart, 2017). From a sociocognitive perspective, stigma comprises three structures: stereotypes, prejudice, and discrimination (Sheehan et al., 2017). Stereotypes pertain to public attitudes. For instance, a common stereotype is the belief that "people diagnosed with mental disorders are dangerous." Prejudices are characterized as emotional reactions stemming from the acceptance of these public attitudes. In the case of the aforementioned example, it would involve affirming that individuals diagnosed with mental disorders are, indeed, dangerous. As a reaction to this belief, individuals may feel uncomfortable sharing a space with someone exhibiting this characteristic. Finally, discrimination is perceived as behaviours that emanate from stereotypes and prejudices. In the context of the example provided, discrimination would manifest as actively avoiding interactions with individuals diagnosed with mental disorders (Krupchanka & Thornicroft, 2017). In essence, stigma operates by generating negative stereotypes about marginalized social groups, which subsequently give rise to social narratives that justify their discrimination (Livingston & Boyd, 2010).

The most common stereotypes associated with mental disorders include perceptions of dangerousness, incompetence, and permanence (Sheehan et al., 2017). Among these, dangerousness is particularly prominent and poses a significant challenge in terms of discrimination. This stereotype revolves around the belief that individuals diagnosed with mental disorders are prone to violence and unpredictability. It is this specific stereotype that significantly impacts people's willingness to be in proximity to those diagnosed with mental disorders (Angermeyer & Matschinger, 2005). Incompetence refers to the belief that individuals with mental disorders are incapable of leading independent lives (Sheehan et al., 2017). This aspect is reflected in the workplace, where derogatory comments about the skills of individuals with mental disorders are often made (Jenkins & Carpenter-Song, 2009). Finally, permanence refers to the perception that mental disorders are severe and chronic (Hayward & Bright, 1997). Consequently, this perception can influence the support received by individuals considered to have a "chronic" problem, diminishing their potential to develop an autonomous life project.

Following Goffman's tradition, mental health stigma operates across three interactive levels: institutional or structural, interpersonal, or social, and individual or personal (Livingston & Boyd, 2010). Structural or institutional stigma pertains to the rules, policies, and procedures of public and private organisations in positions of power that impose restrictions on the rights and opportunities of individuals diagnosed with mental disorders. Social stigma, also referred to as public stigma, involves the creation of stereotypes that work against a stigmatised group (Corrigan et al., 2005). Thus, public stigma stands as the greatest barrier to the social participation of people diagnosed with a mental disorder (Rubio-Valera et al., 2016). Finally, individual, or personal stigma refers to the one experienced from the person's own perspective (Gerlinger et al., 2013). Personal stigma encompasses experienced, perceived, and internalized stigma. Experienced stigma is defined as the encounter with actual discrimination faced by the individual (Gerlinger et al., 2013). Perceived stigma, on the other hand, relates to the subjective perception of being despised and marginalised (Link et al., 2001). Finally, internalized stigma, often referred to as self-stigma, is the acceptance of social stigma (Corrigan & Watson, 2002). This involves a subjective process in which individuals internalize the stereotypes created by society, anticipate rejection, perceive the stereotypes as relevant, and view themselves as devalued members (Corrigan et al., 2005; Livingston & Boyd, 2010).

To combat stigma, various social movements and institutions have initiated campaigns employing strategies such as promoting social contact and educational interventions targeting both general and specific audiences. (Gaebel et al., 2017). In Spain, there are several initiatives promoted by various organisations. Alongside numerous initiatives undertaken by local associations, sometimes coordinated by first-person federations such as "En Primera Persona" in Andalucía, and "Veus" in Catalunya, or by the "Confederación Salud Mental España," an organization stemming from the family movement, there is also the "Chair Against Stigma" at the Complutense University. Additionally, two campaigns with the support of regional governments have been launched: "1 in 4" in Andalusia, named after the statistic, that 25% of the world's population will face a mental disorder in their lifetime, and "Obertament," the Catalan association dedicated to combating stigma and discrimination in mental health. After several campaigns targeted at the general public (Aznar-Lou et al., 2015), Obertament has initiated interventions targeting key actors, including students (Andrés-Rodríguez et al., 2017), social services professionals (Rubio-Valera et al., 2018), and health professionals (Eiroa-Orosa et al., 2021). In this study, our focus will be on interventions specifically directed at health professionals.

Although it may appear paradoxical, health professionals, particularly those specialising in mental health, exhibit discriminatory behaviours towards individuals diagnosed with mental disorders, much like the general population (Henderson et al., 2014; Schulze, 2007). One of the most extensive observational studies conducted to date (Corker et al., 2013) revealed that, with minor temporal fluctuations, approximately 90% of individuals utilizing mental health services in England had encountered at least one episode of discrimination from the health professionals responsible for their care. The perception of the mental health of healthcare personnel is a determinant of the treatment users will receive (Obertament, 2016). Consequently, the professionals' perception of individuals with a mental disorder will influence attitudes towards respecting the rights of users (Eiroa-Orosa & Limiñana-Bravo, 2019) and, by extension, impact the quality of care received (Corrigan, 2004).

Similar to the general population, discriminatory behaviours among mental health professionals stem from stereotypes such as danger, incompetence, and permanence. The coercion employed in certain mental health settings is often rooted in the stereotype of danger (Large et al., 2008). The stereotype of incompetence gives rise to paternalistic attitudes, characterized by interference with a person's freedom of action, justified on the grounds of their well-being or interests (Ramos Montes, 2021). This justification often leads to decision-making without the active participation of the individual, who tends to be treated in an infantilizing manner. Lastly, the stereotype of permanence justifies the prolonged use of psychotropic drugs or the existence of long-term care facilities without a focus on the recovery of a meaningful life project. Conversely, the reductionist perspective on mental health problems by somatic

health professionals can result in errors, such as the phenomenon known as diagnostic eclipse. This entails interpreting symptoms of physical discomfort as a consequence of a mental disorder (Nash, 2013). This phenomenon can have serious consequences, as it may result in the neglect of symptoms that could indicate life-threatening diseases.

The present study

Obertament's initiatives are conceived and executed with the co-leadership of activists—individuals who have personally experienced or are currently experiencing mental health issues. These activists draw from their own experiences to conduct awareness activities aimed at combating stigma. In the awareness sessions facilitated by activists, the concept of stigma and prevailing prejudices surrounding mental health are discussed. Additionally, a life story is shared, highlighting experiences of discrimination and self-stigma. Prior to engaging in such sessions, Obertament provides training to familiarise participants with activism strategies. This space serves as a platform for everyone to develop and share their life stories.

This study aims to analyse the experiences of Obertament activists who have carried out activism actions in the healthcare sector. The selection of this association aligns with its values and objectives in the struggle for the dignity of people, and to spotlight a line of work that is especially intricate yet necessary. Furthermore, to our knowledge, although there is evidence of the effectiveness of interventions against stigma carried out in this sector (Lien et al., 2021), there is no literature that explores the subjective experience of the people carrying out the actions. Therefore, the objective of this study is to understand the subjective experience of Obertament's activists involved in the line of work to combat stigma in the healthcare sector. We aim to gather experiences related to lived experiences of stigma and the efforts to combat it through activism.

METHODOLOGY

To conduct this study, we reached out to five Obertament activists with the intention of conducting semi-structured interviews with each of them. All individuals interviewed possessed experience in activism within the healthcare sector. Furthermore, some of them have also had the opportunity to engage in awareness interventions in educational or media settings.

The interview questions were centred around the awareness activities conducted within the health context, probing into the participants' experiences in carrying out these tasks and their expectations for change through activism. As evident in the results and discussion section, the dynamic nature of the interviews often led to discussions on aspects related to the nature of stigma as a social phenomenon.

We also consider it important to reflect on the research position of the authors of the work. The first author, in addition to an academic role, has taken on activist roles against stigma within the association Obertament. In the case of the second author, a student with no prior experience in activism within this field, she was able to leverage the connections of the first author to conduct the interviews and received supervision to carry out the analysis. Therefore, while the axiological position of both authors reflects a commitment to the cause against stigma, the distribution of tasks facilitated the opportunity for the activists interviewed to share their experiences with someone outside the usual circle of activism.

All the activists interviewed provided signed informed consent. The interviews were recorded using a mobile device and later transcribed, with the exception of one participant who opted to respond to the questions via email. Once transcribed, the texts were inputted into a database within a dedicated qualitative analysis software (ATLAS.ti).

To analyse the data, we opted for a thematic analysis following the methodological framework proposed by Virginia Braun and Victoria Clarke (2006). Thematic analysis enables the identification and analysis of common patterns within the data, which are referred to as themes. One notable advantage of this qualitative analytical method is its flexibility and ease of application, making it particularly accessible for students.

The phases followed to carry out the analysis were as follows:

- 1. Become familiar with the data: Transcription of interviews, annotation of initial ideas.
- 2. Generate initial codes: Encoding fragments with interest according to our objectives.
- 3. Generate themes: Codes are contrasted and their inclusion in a topic is considered.
- 4. Review the themes: It is ensured that the identified themes align with the coded extracts and the entire dataset.
- 5. Define and name themes: It is checked that there is a coherence within each topic, they are given a name, and they are defined.

6. Write the results report: Representative citations are selected as examples for each topic. The entire analysis is related to the literature consulted.

RESULTS AND DISCUSSION

Two overarching thematic blocks have been identified: Stigma and Activism. Each block has been categorised into themes, which result from grouping several codes in a non-exclusive fashion. This means that a code can be associated with multiple themes (refer to Appendix A). For comprehensive details on each topic, including frequencies and examples, please consult Appendix B.

Regarding the Stigma block, the themes created are: Stereotypes and Prejudices, Discriminatory behaviors and Self-stigma. As for the Activism block, the themes created are: Positive Effects, Strategies, and Impact. It has been found appropriate to divide some themes into subthemes, since the different participants have specified Discriminatory behaviors, Positive effects and Concrete strategies.

Below are the definitions of the themes and subthemes mentioned, along with discussions for each section.

Stigma

This block aligns conceptually with the structures of the socio-cognitive model (Sheehan et al., 2017). While *Stereotypes and Prejudices* have been grouped into a single theme, the *Discriminatory Behaviours* component has been divided into two subthemes: vertical gaze and diagnostic eclipse.

Stereotypes and Prejudices

This topic pertains to the beliefs, attitudes, and reactions of society towards individuals diagnosed with a mental disorder from the perspective of activists. It encompasses both public attitudes and emotional reactions. For instance, the stereotype of danger (Corrigan et al., 2005; Sheehan et al., 2017) would be considered part of public attitudes.

One day I went to a dinner party and people were dressed up. I saw a guy wearing a uniform, a whip, and a mask. He said he was an insane asylum patient [sic]. It's that it makes a very clear association with being crazy, being a killer [sic]. It is what we say, if you look at the statistics you see that we are not more violent than the rest, they usually cause violence to us. (Interview 3, personal interview, November 2018)

In the context of the media, activists perceive that the stigma generated at this level poses significant challenges to their work. The reach of the messages is challenging to neutralise despite the continuous efforts of the organisations.

People watch the murder series and of course, "the crazy." It is a very negative image and that is not what they will find in reality (Interview 3, personal interview, November 2018).

The resulting prejudices, such as feeling less secure as a professional on certain devices, would be the emotional reaction stemming from the agreement with this fact (Sheehan et al., 2017). As we will see in the next subtopic, the interplay between these factors could lead to the development of discriminatory behaviours, including paternalism and coercion.

Discriminatory behaviours

This theme encompasses two subthemes related to behaviours observed or experienced by activists. Firstly, Vertical Gaze refers to the power imbalance and, consequently, violations of rights related to paternalism and coercion (Ramos Montes, 2021; Schulze, 2007).

It is to show the authority and here you will do what we tell you and you will take the pill without giving problems because otherwise... (Interview 5, personal interview, December 2018)

And the Medical Tribunal "ruled that I am incapable of anything" ... years ago. [sic] (Interview 2, personal interview, November 2018)

I've been threatened. If you don't take your medication, what do you want, for us to tie you up again? (Interview 5, personal interview, December 2018)

On the other hand, there are testimonies that align with the definition of the concept of diagnostic eclipse, indicating the persistence of this type of discriminatory behaviour already identified in previous studies conducted with the user population of health services in Catalonia (Obertament, 2016).

We explain that a person who has had problems with the arm, for example, has wanted to play with children and has hurt himself. He wants the doctor to pay attention to him and maybe the doctor says, he is already starting to have some symptoms and he does not take it seriously and they do not do a simple X-ray to verify that it is true. (Interview 3, personal interview, November 2018)

If the GP sees that the person has an obsessive disorder and sees that "something" [sic] comes from something organic, physical, which in principle has nothing to do with it, but can attribute it to the disorder. (Interview 4, personal interview, December 2018)

Self-stigma

In all cases, participants mentioned the concept of Self-Stigma (Livingston & Boyd, 2010) at some point. This concept is situated within the broader concept of personal stigma (Gerlinger et al., 2013) and, therefore, pertains to the self-image of the activists. It encompasses ideas reflected in codes such as insecurity, loneliness, pain, and self-blame, resulting from the acceptance of social stigma and the prejudices of professionals. These feelings contribute to the development of behaviours such as hiding the diagnosis or experiencing difficulties in asking for help (Corrigan et al., 2014).

You can't imagine the years I've been blaming myself for being bad and not performing or not getting where I was before. (Interview 2, personal interview, November 2018)

It is true that at work you have to shut up, say nothing. (Interview 3, personal interview, December 2018)

Activism

Positive effects

This theme pertains to the positive feelings that activism evokes among participants and includes the subthemes of Wellbeing and Empowerment. The being subtheme encompasses codes that reflect a state of satisfaction and fulfilment.

And that moment comes and then you decide to start facing your own demons, because you know that this way you can help others and yourself as well. (Interview 2, personal interview, November 2018)

Activists explain that taking actions has increased their self-esteem and sense of usefulness.

It makes me feel very useful, but useful in society, in life. (Interview 5, personal interview, December 2018)

All participants expressed a high level of satisfaction with their roles as activists. It is noteworthy to highlight the code "Usefulness" within the topic of Wellbeing, as all participants referenced it at some point during the interviews. Additionally, the theme of support emerged, with participants explaining that through Obertament, they have connected with individuals facing similar situations, providing a solid support network. This has allowed them to share their experiences and feel more accompanied.

It is discussed so that these people have an example of someone who has recovered, people who are a little lost, restless and such, who have a little more perspective and who know that later, when they leave, they can seek help, that they are not so alone. (Interview 3, personal interview, November 2018)

At the same time, the *Empowerment* subtheme includes codes that reflect feelings of personal growth and accountability.

Most of them you carry in your pocket. I have emerged relatively victorious from most challenges. Relatively. (Interviewed 5, personal interview, December 2018)

Wellbeing and Empowerment are closely intertwined. The aspect of accountability, included in the definition of the Empowerment subtheme, has been considered a distinctive point. The high percentage of presence in this theme, and the fact that both subthemes refer to positive emotions, is indicative of the satisfaction of activists within their activity fighting against stigma. In fact, previous studies conducted with Obertament in training activists (Eiroa-Orosa & Lomascolo, 2018) have already linked these activities to an increase in wellbeing, especially in individuals with high levels of previous self-stigma.

Strategies

Participants explain and highlight a diverse range of strategies they employ when conducting awareness-raising activities. Strategies such as role play, social contact, maintaining a horizontal gaze, fostering naturalness, and initiating self-critical debates are prominently emphasized by the interviewed activists. They also underscore the importance of carrying out these strategies in synergy with the professionals who receive them.

What you have to do is have deft touch, because what is being told are facts and testimonies, someone who has suffered some prejudice, tell specific stories and there comes a time when professionals seem to go there to say that they do it wrong in some way and they get defensive. (Interview 4, personal interview, December 2018)

The strategy that all activists have consistently highlighted as very positive is *First Person*. Therefore, it has been deemed appropriate to distinguish it from the rest of the strategies by forming its own subtheme. The first-person testimony is rooted in what they all refer to as a life story.

What I have learned and is repeated to us a lot is that the first-person testimony, the life story, is the best tool to connect with people and thus be able to start raising their awareness.

And the first person people are the push and the engine, which must be constant, to transform this chrysalis into a beautiful butterfly. (Interview 2, personal interview, November 2018)

This strategy is not novel in the struggle for visibility and the assertion of rights. For many years, it has been a cornerstone for various groups, such as those in the feminist movement or the LGBTI movement (Renn, 2007). One of the guiding principles of Obertament is that the impact of interventions multiplies when conducted by individuals who have personally experienced stigmatising situations (Obertament, 2013). This imparts more legitimacy and credibility and is linked to an empowerment process for the individuals involved.

Impact

The primary objective of this awareness-raising task is to instigate a shift in mindset. In the pursuit of this objective, it is aimed to underscore the impact of activists engaging with mental health professionals. Regarding awareness sessions, activists explain encountering a wide spectrum of responses ranging from complete harmony to a justification of the system, primarily based on the belief that their experiences represent exceptional episodes and do not reflect of daily care practices. The issue of attending voluntarily or compulsorily is also discussed. In numerous instances, centres willingly agree to host these sessions but compel professionals to participate, leading to scepticism. Nonetheless, activists highlight that many professionals are genuinely interested in contributing to this change; they actively seek ways to enhance mental health care from both a personal and structural perspective.

There are many people who want to do it differently, to be more humanitarian, more horizontal, more respectful and to take more into account the opinion and feeling of their patients. (Interview 5, personal interview, December 2018)

I had a very pleasant feeling that mental health does have a great hope of improvement because all these professionals welcomed my life story, and myself, with a lot of respect and even affection. (Interview 2, personal interview, November 2018)

Activists find it positive when professionals engage in a self-critical debate, questioning the daily functioning of mental health services. Moreover, one participant emphasises that a systemic change is imperative for meaningful transformation.

We have to involve politicians; we have to involve the most hierarchical structures because we cannot make them depend only on the good faith of four people. (Interviewed 5, personal interview, December 2018)

This aligns with the findings of evaluations of interventions promoting the Recovery model, where it is evident that a transformation in staff beliefs, attitudes, and behaviours must go hand in hand and be reinforced by provider organisations and the public administration (Eiroa-Orosa & García-Mieres, 2019).

CONCLUSION

In this study, we had the opportunity to analyse the thematic framework present within the testimonies of five activists engaged in a project aimed at addressing stigma within the healthcare context, conducted under the auspices of the Obertament association. Through our analysis, we contextualised the structures outlined by the sociocognitive model of stigma. In the health sector, many prejudices present in other contexts, such as perceptions of danger, incompetence, and permanence, come into play. These stereotypes manifest as prejudices about the behaviour of individuals diagnosed with mental disorders, which are reflected in discriminatory behaviours by professionals who adopt an authoritative position towards service users. These attitudes further reinforce the self-stigma experienced by those affected. Within this context, the activism of Obertament emerges. Activists, drawing from their personal experiences, intervene to combat stigma in mental health, seeking to alter stereotypes towards individuals diagnosed with mental disorders. Activism activities generate feelings of well-being and empowerment, contributing to the reduction of their self-stigma.

One limitation of this study is the small number of participants interviewed. The sample size is small, although it is proportionally representative of Obertament activists engaged in awareness-raising activities in the health sector. Notably, one of the interviewees joined the Obertament team specifically to conduct interventions in the health field that were continuous and thoroughly evaluated (Eiroa-Orosa et al., 2021). While the interviewed individuals form a representative group both in terms of their experience and the proportion, they represent within the total number of activists working in the health field, it is plausible that interviewing more activists could have enhanced theoretical saturation (Saunders et al., 2018) and, consequently, provided a more robust understanding of the experience of activism in this context. Nevertheless, considering the available resources for this research action, we believe we have constructed a coherent thematic structure that illuminates the subjective experience of individuals engaged in this type of activism.

Future lines of work could explore the subjective experiences of activists in other contexts, such as work or education, and even activists with experiences in multiple domains. Such initiatives could provide insights into strategies to enhance the experience of individuals embarking on their activism journey.

In conclusion, despite the existence of stigma towards individuals diagnosed with mental disorders posing a hindrance to recovery, activism provides valuable tools for resilience and social transformation. In this regard, activism serves a dual purpose. On one hand, it aims to dismantle certain stereotypes ingrained in mental health professionals to prevent discriminatory behaviour. On the other hand, concerning the subjective experience of activists, it provides a collective space for understanding, support, and action that can aid in overcoming self-stigma.

APPENDIX A. DEFINITION OF CODES AND CLASSIFICATION INTO SUBTHEMES, THEMES AND BLOCKS

BLOCK			
Theme	Definition		
Subtheme			
Codes			
TIGMA			
Stereotypes and Prejudices			
Violent	Specific situations in which they have felt identified as violent.		
Mental health image	Perception that there is an image of mental health not shared among all the agents involved.		
Exceptionality	The belief of mental health professionals that the discrimination situations that the activist explains are exceptional situations.		
Insane	Specific situations in which they have been identified as crazy people.		
Invisibility	Perception that mental health problems are less legitimate as they are less visible than somatic ones		
Media	Presence of stereotypes towards people with diagnoses of mental disorder in the media.		
Discriminatory behaviour			
Vertical Gaze			
Violation of rights	Violation of people's rights by professionals.		
Disempowerment	Prevent the development of an autonomous life project.		
Incapacitation	Judgment of a medical court in which the person is incapacitated to work.		
Threats	Specific threats they have received from professionals.		
Paternalism	Overprotective behaviour by professionals or family members.		
Motherhood	Recommendation by professionals not to exercise motherhood.		
Derogatory vocabulary	Vocabulary used in society towards mental disorders without being aware of what can harm.		
Improper treatment	Fragments in which activists explain that the treatment by professionals is not appropriate.		
Mechanical restraint	Situations in which professionals restrain the service user.		
Diagnostic eclipse	Situations in which symptoms of physical discomfort have been interpreted as a result of a mental dis		
Diagnostic eclipse	order without any further investigation.		
Self-stigma			
Shame and loneliness	Assuming that loss of relationships is an inevitable consequence of diagnosis.		

BLOCK Theme					
	theme	Definition			
5401	Codes				
	Difficulty asking for help	Problem asking for help because of the prejudices you have.			
Pain		Anguish and suffering caused by receiving a diagnosis.			
Self-blame		Blaming yourself for feeling sick and not reaching set goals.			
	Hide	Hiding the diagnosis. Both at work and from family and friends.			
	Insecurity	Worry, fear, having a hard time when starting to be activists.			
	,				
Positiv	ve effects				
Wel	lbeing				
	Referents	Feeling of serving as a reference for other people in similar situations			
	Understanding	Feeling of being understood by fellow activists.			
	Stability	Feeling good, having control of oneself to carry out the task of mobilizing well.			
	Self-esteem	Reinforce positive feelings towards themselves.			
	Safety	Feel safe in the face of the awareness tasks.			
	Strength	Energy in taking responsibility and fighting for one's own rights.			
	Clash	Feeling of struggle against one's own fears.			
	Confidence	Self-confidence derived from the awareness-raising work carried out.			
	Self-knowledge	Get to know each other more thanks to the elaboration of a life story and lived experiences.			
	Pride	Feel happy and proud of the work done.			
	Usefulness	Feel useful for oneself and for society to be contributing to the change of mentality.			
	Visibility	Go out and stand up in order to be seen.			
	Support	Find support in other activists and colleagues who have gone through similar situations.			
	Taking off Self-blame	Realize that you are not guilty of your own diagnosis.			
	Confidences	Share experiences with other colleagues during training for activists or GAMs.			
	Efficacy	Feeling of convincing professionals of what is explained.			
Fmr	powerment				
Emp	Self-knowledge	Get to know each other more thanks to the elaboration of the life story and the lived experiences.			
	Referents	Feeling of convincing professionals of what is explained.			
	Efficacy	Feeling of convincing professionals of what is explained.			
	Self-esteem	Reinforce positive feelings towards themselves.			
	First person	Talk about your own experience.			
	Trainers	Identify with a role of trainer rather than a diagnosed person or service user.			
	Expose privacy	Feel safe while exposing intimate situations in front of the audience to which the session is addresse			
	Stand up	Dare to stand up and show up to people with prejudices.			
	Personal experience				
Strate		Feeling that sharing the experience has an effect on reducing stigma among health personnel.			
Juale	Normalize	Talk about Mental Health as normal.			
	Find middle ground	Adapt to the public according to their needs.			
	Reach everyone	Reach professionals who are not sure what stigma is and its existence, because many times these are the ones who do not attend the sessions.			
	Claim rights	Claiming the rights of people with mental health problems			
	Role playing	A dynamic in which the public takes on the role of the professional and the service user in order to p themselves in their shoes.			
	Continuous training	Done by, as a mobilizer, being well trained and up to date.			
	New perspectives	Open the public to consider new visions through explanations of concepts and experiences.			
	Perceptions change	Cause a change in the perception that exists about mental health.			

OCK Theme		Definition			
Subt		Definition			
	Codes				
	Systemic change	Involve the whole system (politicians, hierarchical structures) in change.			
	Focus on Recovery	Talking about the recovery process ahead of suffering.			
	Definition of Mental Health	Ask professionals to define the term mental health to observe from which point it starts.			
	Life story	Explaining your own experience.			
	Horizontal look	Position of professionals towards service users, who prioritize the first person. It would correspond to moving away from the paternalistic approach.			
	Obertament Training	Training provided by Obertament to train in activism.			
	Debate among professionals	Create debate among professionals where they can show their diverse opinions.			
	No dramatising	Develop the session away from the role of victim.			
	Tact	Act with the left hand, prevent professionals from feeling attacked.			
	Continuous work	Fragments in which it is explicit that continuous work is necessary to achieve changes.			
	Naturalness	Explain naturally, how it comes out from the inside.			
	Humanize professionals	Work with professionals from their facet as people. In this way invite them to realize that they also experience contradictory thoughts and developed attitudes.			
	Training to combat stigma for professionals	Talk about stigma and prejudice around mental health.			
Firs	t person				
	Expose privacy	Expose intimate situations in front of the audience to which the session is addressed.			
	Refute with experience	Strength of being talking about your own experience and thinking that no one can refute your life.			
	Life story	Explaining one's own experience with a mental disorder.			
Impact					
	Systemic change	Involve the whole system (politicians, hierarchical structures) in change.			
	Evolution	Belief that there has been a favourable evolution with respect to SM stigma in recent years.			
	Hope for change	Belief in the fact that the message of awareness arrives that can lead to the change of mentality.			
	Change in perceptions	Cause a change in the perception that exists about mental health.			
	Critical professionals	Position adopted by professionals when analysing their behaviour. Many times, they become the sam judges of their medical malpractices.			
	Obliged professionals	Compulsory attendance (required by the workplace) to activist sessions. This can create a more scep tical environment.			
	Feeling questioned	Sentiment of professionals in which they receive criticism towards their medical practices as an at- tack.			
	Interest	Curiosity, paying attention, desire of professionals to change attitudes.			
	Diversity of reception	Perception of the fact that some professionals are highly motivated by change and others are very sceptical.			
	Healthy discussion between professionals	Create debate among professionals where they can show their diverse opinions.			

APPENDIX B. FREQUENCIES OF EACH TOPIC AND SUBTOPIC OF THE ANALYSIS: NUMBER OF CITATIONS IN WHICH IT APPEARS, NUMBER OF WORDS THAT REFER TO EACH TOPIC, THEIR CORRESPONDING PERCENTAGES AND EXAMPLE OF CITATIONS EXTRACTED FROM THE INTERVIEWS

Themes	Citations	%	Words	%	Example citations
ESTIGMA					
Stereotypes and Prejudices	12	6,28	531	7,58	"It makes a very clear association with being crazy, being a murderer" "If you see the examples in the press: schizophrenic, all the vocabulary used is perhaps very discriminatory and a change should be made in that. Politi- cians have it, the media have it".
Discriminatory behaviours	16	8,38	719	10,28	
Vertical Gaze	14	7,33	587	8,39	"It is to show the authority and here you will do what we tell you and you will take the pill without giving problems because otherwise".
Diagnostic eclipse	2	1,05	132	1,88	"If the GP sees that the person has an obsessive disorder and sees that something comes from something organic, physical, which in principle has nothing to do with it, but can attribute it to the disorder".
Autoestigma	14	7,33	409	5,84	"You can't imagine the years I've been blaming myself for being bad and not performing or not getting where I did before".
ACTIVISM					
Positive effects	55	28,80	1624	23,22	
Wellbeing					"It makes me feel very useful, but useful in society, in life".
wellbeing	43	22,51	1012	14,47	"They helped me to first realize that I have a vast peer group and to realize that I am not the cause of my illness".
Empowerment	12	6,28	612	8,75	"What we are doing is a necessary step () when a person comes out and stands firm, we must also dare to stand up".
Strategies	63	32,98	2690	38,46	"I don't like to be the victim, I don't like to dramatize too much or put a lot of emphasis on my suffering".
2		,		,	"We actively participate in the talk, so one acts as a psychologist, the othe as a patient".
First person	17	8,90	913	13,05	"What I have learned and is repeated a lot is that the first-person testimo- ny, the life story, is the best tool to connect with people and thus be able to start raising awareness".
					"And what I loved was to see how the same professionals spontaneously be- came judges and lecturers of medical malpractice".
Impact	31	16,23	1020	14,58	"There are many people who want to do it differently, to be more humani- tarian, more horizontal, more respectful and to take more into account the opinion and feeling of their patients".

REFERENCES

Andrés-Rodríguez, Laura; Pérez-Aranda, Adrián; Feliu-Soler, Albert; Rubio-Valera, Maria; Aznar-Lou, Ignacio; Serrano-Blanco, Antoni; Juncosa, Miquel; Tosas, Anaïs; Bernadàs, Albert & Luciano, Juan V. (2017). Effectiveness of the "What's Up!" Intervention to Reduce Stigma and Psychometric Properties of the Youth Program Questionnaire (YPQ): Results from a Cluster Non-randomized Controlled Trial Conducted in Catalan High Schools. *Frontiers in Psychology*, 8(SEP), 1-12. https://doi.org/10.3389/fpsyg.2017.01608

- Angermeyer, Matthias C. & Matschinger, Herbert (2005). Labeling Stereotype Discrimination: An investigation of the stigma process. Social Psychiatry and Psychiatric Epidemiology, 40(5), 391-395. <u>https://doi.org/10.1007/s00127-005-0903-4</u>
- Aznar-Lou, Ignacio; Serrano-Blanco, Antoni; Fernández, Ana; Luciano, Juan V. & Rubio-Valera, Maria (2015). Attitudes and intended behaviour to mental disorders and associated factors in catalan population, Spain: cross-sectional population-based survey. BMC Public Health, 16(1), 127. <u>https://doi.org/10.1186/s12889-016-2815-5</u>

Braun, Virginia & Clarke, Victoria. (2006). Using thematic analysis in psychology. Qualitative Research in Psychology, 3(2), 77-101. https://doi.org/10.1191/1478088706qp063oa

- Corker, Elizabeth; Hamilton, Sarah; Henderson, Claire; Weeks, Craig; Pinfold, Vanessa; Rose, Diana; Williams, Paul; Flach, Clare; Gill, Valdeep; Lewis-Holmes, Elanor & Thornicroft, Graham. (2013). Experiences of discrimination among people Using mental health services in England 2008-2011. British Journal of Psychiatry, 202(s55), s58-s63. <u>https://doi.org/10.1192/bjp.bp.112.112912</u>
- Corrigan, Patrick W. (2004). How stigma interferes with mental health care. *American Psychologist*, 59(7), 614-625. <u>https://doi.org/10.1037/0003-066X.59.7.614</u>
- Corrigan, Patrick W.; Druss, Benjamin G. & Perlick, Deborah A. (2014). The Impact of Mental Illness Stigma on Seeking and Participating in Mental Health Care. *Psychological Science in the Public Interest*, *15*(2), 37-70. <u>https://doi.org/10.1177/1529100614531398</u>
- Corrigan, Patrick W.; Kerr, Amy & Knudsen, Lissa (2005). The stigma of mental illness: Explanatory models and methods for change. *Applied and Preventive Psychology*, 11(3), 179-190. <u>https://doi.org/10.1016/j.appsy.2005.07.001</u>
- Corrigan, Patrick W. & Watson, Amy C. (2002). Understanding the impact of stigma on people with mental illness. *World Psychiatry*, 1(1), 16-20. <u>http://www.ncbi.nlm.nih.gov/pubmed/16946807</u>
- Eiroa-Orosa, Francisco José & García-Mieres, Helena (2019). A Systematic Review and Meta-analysis of Recovery Educational Interventions for Mental Health Professionals. Administration and Policy in Mental Health and Mental Health Services Research, 46(6), 724-752. <u>https://doi.org/10.1007/s10488-019-00956-9</u>
- Eiroa-Orosa, Francisco José & Limiñana-Bravo, Laura (2019). An Instrument to Measure Mental Health Professionals' Beliefs and Attitudes towards Service Users' Rights. *International Journal of Environmental Research and Public Health*, 16(2), 244. <u>https://doi.org/10.3390/ijerph16020244</u>
- Eiroa-Orosa, Francisco José & Lomascolo, María (2018). Training mental health activists increases the well-being of participants with high baseline levels of self-stigma: results of the Obertament training evaluation. *American Journal of Orthopsychiatry*, *88*(6), 617-625. <u>https://doi.org/10.1037/ort0000376</u>
- Eiroa-Orosa, Francisco José; Lomascolo, María & Tosas-Fernández, Anaïs (2021). Efficacy of an Intervention to Reduce Stigma Beliefs and Attitudes among Primary Care and Mental Health Professionals: Two Cluster Randomised-Controlled Trials. *International Journal of Environmental Research and Public Health*, 18(3), 1214. <u>https://doi.org/10.3390/ijerph18031214</u>

- Gaebel, Wolfgang; Rössler, Wulf & Sartorius, Norman (Eds.) (2017). The Stigma of Mental Illness - End of the Story? Springer. https://doi.org/10.1007/978-3-319-27839-1
- Gerlinger, Gabriel; Hauser, Marta; De Hert, Marc; Lacluyse, Kathleen; Wampers, Martien & Correll, Christoph U. (2013). Personal stigma in schizophrenia spectrum disorders: A systematic review of prevalence rates, correlates, impact and interventions. World Psychiatry, 12(2), 155-164. <u>https://doi.org/10.1002/wps.20040</u>
- Goffman, Erving (1963). Stigma: Notes on the Management of Spoiled Identity. Prentice-Hall.
- Goldman, Howard H. & Morrissey, Joseph P. (1985). The alchemy of mental health policy: homelessness and the fourth cycle of reform. *American Journal of Public Health*, 75(7), 727-731. <u>https://doi.org/10.2105/AJPH.75.7.727</u>
- Hayward, Peter & Bright, Jenifer A. (1997). Stigma and mental illness: A review and critique. *Journal of Mental Health*, 6(4), 345-354. <u>https://doi.org/10.1080/09638239718671</u>
- Henderson, Claire; Noblett, Jo; Parke, Hannah; Clement, Sarah; Caffrey, Alison; Gale-Grant, Oliver; Schulze, Beate; Druss, Benjamin & Thornicroft, Graham. (2014). Mental health-related stigma in health care and mental health-care settings. *The Lancet Psychiatry*, 1(6), 467-482. <u>https://doi.org/10.1016/S2215-0366(14)00023-6</u>
- Hervey, Nicholas (1986). Advocacy or folly: The Alleged Lunatics' Friend Society, 1845-63. *Medical History*, *30*(03), 245-275. <u>https://doi.org/10.1017/S0025727300045701</u>
- Jenkins, Janis Hunter & Carpenter-Song, Elizabeth A. (2009). Awareness of Stigma Among Persons With Schizophrenia. *The Journal of Nervous and Mental Disease*, 197(7), 520-529. https://doi.org/10.1097/nmd.0b013e3181aad5e9
- Krupchanka, Dzmitry & Thornicroft, Graham (2017). Discrimination and Stigma. In Wolfgang Gaebel, Wulf Rössler & Norman Sartorius (Eds.), The Stigma of Mental Illness - End of the Story? (pp. 123-139). Springer. <u>https://doi.org/10.1007/978-3-319-27839-1_7</u>
- Large, Matthew M.; Ryan, Christopher J.; Nielssen, Olav B. & Hayes, Rachel A. (2008). The danger of dangerousness: why we must remove the dangerousness criterion from our mental health acts. *Journal of Medical Ethics*, *34*(12), 877-881. <u>https://doi.org/10.1136/jme.2008.025098</u>
- Lien, Yin-Yi; Lin, Hui-Shin; Lien, Yin-Ju; Tsai, Chi-Hsuan; Wu, Ting-Ting; Li, Hua & Tu, Yu-Kang (2021). Challenging mental illness stigma in healthcare professionals and students: a systematic review and network meta-analysis. *Psychology & Health*, *36*(6), 669-684. https://doi.org/10.1080/08870446.2020.1828413
- Link, Bruce G.; Struening, Elmer L.; Neese-Todd, Sheree; Asmussen, Sara; Phelan, Jo C.; Consequences, The; With, People & Illnesses, Mental. (2001). Stigma as a barrier to recovery: The consequences of stigma for the self-esteem of people with mental illnesses. *Psychiatric Services*, 52(12), 1621-1626.
- Link, Bruce G. & Stuart, Heather (2017). On Revisiting Some Origins of the Stigma Concept as It Applies to Mental Illnesses. In Wolfgang Gaebel, Wulf Rössler & Norman Sartorius (Eds.), *The Stigma of Mental Illness - End of the Story?* (pp. 3-28). Springer. <u>https://doi.org/10.1007/978-3-319-27839-1_1</u>

- Livingston, James D. & Boyd, Jennifer E. (2010). Correlates and consequences of internalized stigma for people living with mental illness: A systematic review and meta-analysis. *Social Science and Medicine*, 71(12), 2150-2161. <u>https://doi.org/10.1016/j.socscimed.2010.09.030</u>
- Nash, Michael (2013). Diagnostic overshadowing: a potential barrier to physical health care for mental health service users. *Mental Health Practice*, 17(4), 22-26. <u>https://doi.org/10.7748/mhp2013.12.17.4.22.e862</u>
- Obertament (2013). Estrategias de lucha contra el estigma en salud mental. *Dossiers Del Tercer Sector*, 26, 1-18.
- Obertament (2016). L'estigma i la discriminació a la atenció a la salut. https://www.spora.ws/wp-content/uploads/2017/03/2016.-Cat.-Estigma-i-Salut.pdf
- Ramos Montes, Josep (2021). Paternalismo y autonomismo en la relación de ayuda: una reflexión desde la salud mental. *Folia Humanística*, 2(4), 1-21.
- Renn, Kristen A. (2007). LGBT Student Leaders and Queer Activists: Identities of Lesbian, Gay, Bisexual, Transgender, and Queer Identified College Student Leaders and Activists. *Journal of College Student Development*, *48*(3), 311-330. <u>https://doi.org/10.1353/csd.2007.0029</u>
- Rubio-Valera, Maria; Aznar-Lou, Ignacio; Vives-Collet, Mireia; Fernández, Ana; Gil-Girbau, Montserrat & Serrano-Blanco, Antoni (2018). Reducing the Mental Health-Related Stigma of Social Work Students. *Research on Social Work Practice*, 28(2), 164-172. <u>https://doi.org/10.1177/1049731516641492</u>
- Rubio-Valera, Maria; Fernández, Ana; Evans-Lacko, Sara; Luciano, Juan Vivente; Thornicroft, Graham; Aznar-Lou, Ignacio & Serrano-Blanco, Antoni (2016). Impact of the mass media OBERTAMENT campaign on the levels of stigma among the population of Catalonia, Spain. *European Psychiatry*, *31*, 44-51. <u>https://doi.org/10.1016/j.eurpsy.2015.10.005</u>
- Sashidharan, Sashi P.; Mezzina, Roberto & Puras, Dainius (2019). Reducing coercion in mental healthcare. *Epidemiology and Psychiatric Sciences*, 28(6), 605-612. <u>https://doi.org/10.1017/S2045796019000350</u>
- Saunders, Benjamin; Sim, Julius; Kingstone, Tom; Baker, Shula; Waterfield, Jackie; Bartlam, Bernadette; Burroughs, Heather & Jinks, Clare (2018). Saturation in qualitative research: exploring its conceptualization and operationalization. *Quality & Quantity*, 52(4), 1893-1907. <u>https://doi.org/10.1007/s11135-017-0574-8</u>
- Schulze, Beate (2007). Stigma and mental health professionals: A review of the evidence on an intricate relationship. *International Review of Psychiatry*, 19(2), 137-155. <u>https://doi.org/10.1080/09540260701278929</u>
- Sheehan, Lindsay; Nieweglowski, Katherine & Corrigan, Patrick W. (2017). Structures and Types of Stigma. In Wolfgang Gaebel, Wulf Rössler & Norman Sartorius (Eds.), *The Stigma of Mental Illness - End of the Story*? (pp. 43-66). Springer. <u>https://doi.org/10.1007/978-3-319-27839-1_3</u>
- Vázquez-Barquero, José Luis & García, José (1999). Deinstitutionalization and psychiatric reform in Spain. *European Archives of Psychiatry and Clinical Neuroscience*, 249(3), 128-135. <u>https://doi.org/10.1007/s004060050077</u>

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