

Rights, Identity, Neoliberalism: An Exploratory and Critical Analysis of French-speaking Schizophrenia Pages on Facebook

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This article presents an exploratory socio-representational study of French-speaking schizophrenia activism on Facebook. Through a thematic analysis of 100 posts per page, we analyzed how two activist pages presenting differences in their organization (e.g. funded or not) constitute the identity of people with schizophrenia and how they position the latter *vis-à-vis* the social order. The funded page propagates a recovery and public health approach presenting points of contact with neoliberalism. By contrast, the peer-run page aims to combat repressive practices and policies and alter dominant representations. We discuss these results in terms of modes of communication positioning pages and audiences toward the social order. We conclude that Facebook provides a compelling platform for the critical study of digital health activism in France and beyond.

Keywords: Health activism; schizophrenia; Facebook; Social Representations; neoliberalism

INTRODUCTION

In the French context, the active participation of mental health users to mental health planning and practices is a rather recent phenomenon. In this new configuration, the Internet and digital media seem to play an increasingly important role in mental health community participation. In particular, Social Networking Sites (SNS), have created new venues and opportunities in the way health activism is enacted and performed (McCosker, 2018). More than ever, people suffering from or at risk of a specific disorder or condition use Internet resources, such as SNS, websites, blogs and forums in order to seek information (Jacobs et al., 2017), one of the many possibilities these platforms offer their users. Health participation and citizenship on the Internet are very controversial topics with some authors being rather optimistic about the potential of SNS, while focusing on their democratizing and decentralizing potential (Vicari & Cappai, 2016), as well as the possibilities of belonging to a supportive network, which can help counter stigma and increase consumer activation (Naslund et al., 2016). Other authors underline the risks of this ‘peer activation’ through SNS, while expressing concerns that encompass peer activation in general, such as a potentially low credibility of information exchange or even confusion about one’s condition (Ziebland & Wyke, 2012).

The active role of patients and citizens in the politics of health and illness is of course not entirely new, nor a specificity of SNS, and sociological concepts such as *identity politics* (Anspach, 1979) have already offered descriptions of how citizens grouped into medical categories act collectively to bring about change at political, social or even personal level, through a political struggle to alter representations associated with those identities rather than reformist efforts to incorporate categories in the social order. More recently, the concept of ‘evidence-based activism’ has been formulated, in order to describe a new, ‘reformist’ kind of activism that seeks to “engage with and articulate a variety of credentialed knowledge and ‘experiential knowledge’” (Rabeharisoa et al., 2014, p. 111). Groups and associations engaging in this kind of activism have been described as less confrontational, aiming mostly to “make themselves part and parcel of the networks of expertise on their conditions in their national contexts, and to compile evidence on the issues they deem important to address” (Rabeharisoa et al., 2014, p 111).

Moreover, authors have underlined and demonstrated logics associated to neoliberalism underpinning health activism on digital media and SNS. For instance, Petersen et al. (2018), coined the term bio-digital citizenship to highlight the shift from a rights-focused struggle towards “striving to achieve a public profile and attract funding” (Petersen et al., 2018 p. 478) in line with the intense commodification of activism in the neoliberal era. Beyond the purely economical aspects of this link with neoliberal logics, authors have underlined the dissemination of the ‘advanced liberal regime of the self’ (Rose, 1996a), meaning the construction of the responsible and “prudent yet enterprising individual, actively shaping his or her life through acts of choice” (Rose & Novas, 2007). Critical enquiries of e-health pages, drawing on a discourse analytical framework, have provided evidence for a neoliberal ethos underlying discursive productions stemming from Facebook pages. For instance, a study on a Facebook dementia page showed how posts on a page administered by a prominent Australian dementia organization functioned to “make relevant and manage accountability and identity, and position users as responsible for risk-management” (Lawless et al., 2018, p. 44). In the same vein, a critical discursive analysis on diabetes related Facebook pages has shown that the analyzed pages position audiences as ‘informed health consumers, fundraisers and campaign participants’ and transform personal self-management “to a network activity built around sociality’ and exhort users to take responsibility for their lifestyles and risk reduction” (Hunt & Koteyko, 2015, p. 459).

It becomes thus evident that the users’ health activism and participation is a complex albeit interesting phenomenon, that is involves issues of identity and even the relation to the social order. We consider therefore digital activism and participation to be a particularly pertinent locus of enquiry, with Facebook and its affordances offering a fecund platform for such enquiry.

Research on Facebook Pages

Amongst digital media and SNS, Facebook is certainly one of the most widely used social network around the globe (Hunt et al., 2015). One of Facebook’s numerous possibilities of use is as a platform for the creation of health-related pages, that can be related to health information, peer self-help and experience sharing, policy discussion and even activism. Therefore, it also provides an interesting platform for the study of the expression of illness identity and its management, as well as health activism. The study of Facebook pages has only recently started

attracting systematic attention and has mostly concerned pages whose objective is information exchange and mental health literacy, either with research aiming to identify their uses and functions (Abramson et al., 2015), or with enquiry into the normative and power issues underpinning discursive styles and content. Facebook pages are a particular *milieu* for health-related activities and content, since for example, compared to online support groups where participants are anonymous, page audiences are at least visible through their profiles (Lawless et al., 2018). Moreover, Facebook pages are frequently administered by institutions and associations, that are either not-for profit, or have financial interests, contrary to online support groups that are in most cases administered by individuals concerned by the disorder. Thus, Facebook pages allow organizations to “dominate the main content” (Lawless et al., 2018, p. 45), filter information, censor commentary and even shape which identities, stories and narratives become relevant.

A Socio-Representational Perspective on Digital Activism and Community Participation

All the above demonstrate that health-related activism and especially in its digital form is a phenomenon that is fundamentally complex and that needs to be studied in relation to questions of sociopsychological processes shaping identity and further, in relation to the ways in which digital forms of activism imply and shape individuals’ relation to the social edifice. Since with our work we intend to analyze such (mental) health participation in a ‘natural’ context in which digital communication takes place, we need an analytical approach that allows us to explore those a) in a contextualized and holistic way and b) in relation to their positioning towards social order.

Therefore, in the present study, our approach is informed by the perspective of Social Representations (SR) (Jodelet, 1991; Moscovici, 1988). SR can be defined as “systems of commonsense knowledge and social practice” (Howarth et al., 2014, p. 19), that serve (a) to establish a social order that enables individuals to orientate themselves and master the material and social world they live in, and (b) to enable communication among members of a community through a shared code for social exchange and for naming and classifying various aspects of the social world including their individual and group history (Sammut & Howarth, 2014). The SR approach allows us to explore the constitution of ‘social thought’ and that, in a particular mediational context where according to Moscovici, group representations become concrete and allow participation in virtual communities (Casalegno, 2005).

From a social and political participation perspective, SR “provide the lens through which to view and create social and political realities, mediate people’s relations with these socio-political worlds and defend cultural and political identities” (Howarth et al., 2014, p. 19). SR theorists have insisted on both the consensual and the fragmented and conflictual nature of this system of SR, both among and within social groups. According to Staerklé, the study of SR can offer insights related to psychosocial processes sustaining the *status quo*, most importantly concerning issues of both consensus and conflict (Staerklé, 2015). At the level of their content, SR can be hegemonic, playing the ideological role of promoting and legitimizing dominant and unjust systems of rule, or can be oriented towards the re-appropriation of meanings and values related to the group, and even to social change and justice. This view of SR accounts for a dynamic perspective on the socio-symbolic issues encompassing and shaping the establishment and legitimization, as well as negotiation, conflict and transformation of the social order (Staerklé, 2016).

Besides the content of SR, communicational processes have also been the object of systematic study, concerning the socio-psychological phenomena related to participation and its relation to social order establishment/transformation. Thus, a line of research has focused on the communicative processes that help to ‘stabilize and to challenge’ social order, in view of group-related processes and issues (Staerklé, 2009). For instance, Staerklé (2015), based on Moscovici’s pioneering research and extending beyond it, has suggested that three different modes of communication defined by Moscovici, namely *diffusion* (i.e. communication of the representational ‘common field’), *propagation* (i.e. a strategic dominant attempt to construct consent) and *propaganda* (i.e. minority attempts to promote alternative representations and social change) can be differentially put to use for the negotiation or even struggle over social order legitimization or transformation.

This line of research on SR and different communication processes related to groups’ positioning in the matrix of social relations within the social order, has only recently started being used for the study of Facebook affordances generally, and has not been applied to the study of health activism more particularly. However, previous socio-representational studies of health-related phenomena has offered us important insights into the ideological and normative underpinnings of knowledge and practices in regards with health and illness (Apostolidis & Dany, 2012).

The Case of Schizophrenia

Thus, our research aims to provide innovative insights on Facebook pages by focusing on a condition that, to our knowledge, has not been the object of such previous study, namely schizophrenia. Schizophrenia is a particularly interesting subject for the study of Facebook health pages for several reasons. First of all, to the extent that it offers an identity to people diagnosed with it, this disorder constitutes a prototype of ‘spoilt identity’ (Goffman, 1963). Schizophrenia is one of the most stigmatized disorders, associated with stereotypes of dangerousness and uncontrollable behavior (Pescosolido et al., 2013), and people suffering from it are victims of structural stigma (Rüsch et al., 2005), discrimination in areas such as housing and employment and rights abuse (Drew et al., 2011). Research has also revealed that stigmatizing discourses penetrate the self-conception of people with schizophrenia, who interiorize negative stereotypes, which can lead to further exclusion and to negative mental health outcomes (Corrigan et al., 2009).

Moreover, being a severe mental disorder, schizophrenia is one of the most contested conditions, both at social and institutional level. Much debate still exists today about the causes (Rose, 2016), the treatments (Weinmann et al., 2009), and even the name (Sartorius et al., 2014) of schizophrenia. Contrary to physical conditions, the biological causes of schizophrenia and, of course, its medical treatment have been contested since the day they appeared, both inside and outside the medical profession, and part of the activism of users and other people concerned is related to a change of paradigm, from a biologizing, psychiatric one, towards a more recovery-oriented and rights-based one (Frese et al., 2001). Moreover, these critiques have moved from the minority, oppositional camp of users’ associations and movements to international institutions, such as the WHO and prestigious psychiatric associations (Bhugra et al., 2017), and quite recently the French state, which have moved towards a recovery-oriented, rights-based mental health model. The goal of such developments is, among others, to shift the focus from hospital care and psychiatry towards the active engagement and capacity-building of people with mental disorders, the strengthening of community mental health services and the fight against stigma and exclusion. However, here again, one has to refer to the numerous critiques of this transformation as related to neoliberal logic, with a focus on autonomisation and responsabilisation, in relation to ‘workfare’ and burden discourses (Peck, 1998).

All the above show the importance of systematic work on activism styles on SNS and elsewhere in relation to mental disorders, and more specifically, schizophrenia. Hence, in this study, we aim to contribute to the study of French-speaking schizophrenia-related Facebook

pages with an exploratory research on pages that place activism at the heart of their objectives. Since our study focuses on positioning *vis-à-vis* the social order and is influenced by works showing the importance of pages' organizational factors (e.g. funding source and centralization) on the disseminated content, we focused on pages that present differences at the level of their participation in the 'activism market' (i.e. funded or not), as well their centralized or self-managed organization (i.e. whether they are managed by mental health associations and institutions or managed by users in a more horizontal manner).

We aim thus to address the following questions:

1) How is identity of people with schizophrenia constituted through the socio-representational contents and processes mobilized by the pages' posts?

2) Based on our data, as well as previous works, how do representational contents and processes position people with schizophrenia toward the social order and in particular, what are the points of contact with the neoliberal logic?

MATERIALS AND METHODS

Facebook Pages

As in previous research (Hunt & Koteyko, 2015), we searched for schizophrenia pages on Facebook by entering "schizophrenia" and "schizophrenic" into Facebook's search function. We identified two major French-speaking pages for schizophrenia: a) the 'Schizophrenias Collective' (Collectif Schizophrénies) and b) 'The schizophrenias' (Les schizophrénies) which explicitly present a kind of activism and public struggle as one of the major objectives in their description section. The content of both pages was publicly available at the time of the extraction and the posts are "considered public information and can be accessed by anyone" (Lawless et al., 2018, p 46). At the time of the extraction (26/10/2018), the two pages had a comparable number of likes (1921 for 'Schizophrenias Collective' and 1654 for 'The schizophrenias'). The page 'Schizophrenias Collective' is a state-funded (which also accepts and encourages individual donations) coalition of different private and state-funded associations, while 'The schizophrenias' is an independent, peer-administered page and Internet site, that does not present any funding source, either on their page, or on their site.

Analytical procedure

Given the exploratory character of our study, we chose to analyze a limited amount of posts while however covering an important amount of time (at least 5 months): Thus and similarly to previous research (Hunt & Koteyko, 2015), we extracted the 100 most recent posts and submitted them to analysis (25/5/2018 – 24/10/2018 for the ‘Schizophrenias Collective’ and 26/6/2016 - 26/10/2018 for ‘The schizophrenias’). In relation to our objectives, we focused on two different levels of analysis. Firstly, in line with our objective of exploring the representational contents of the two pages and drawing on previous research on the uses of a Facebook page on breast cancer (Abramson et al., 2015) and previous SR research (Kalampalidis & Apostolidis, 2016), we performed an inductive, bottom-up content analysis. In line with our main objective, the leading question here was *how analyzed contents present/constitute the identity of people with schizophrenia* and therefore each identified code corresponded to a different theme regarding the identity of people with schizophrenia. Using a researcher triangulation approach (Denzin, 2009), the first two authors read the selected posts several times and then proceeded to perform a separate open coding, which allowed the two authors to create a first coding schema. This procedure was carried out for posts from both pages. Then, the two authors compared their analysis and reached an agreement on a common coding schema. The final version is the result of discussion among all three authors.

After this first inductive thematic analysis, we carried out a selective analysis focusing on *how the socio-representational contents and communicational processes position people with schizophrenia toward the social order* and more precisely, on the *representational points of tension and of contact with the neoliberal logic*, as described in the introduction section. We were particularly interested in the socio-representational positioning regarding the neoliberal active and responsible subject, as well as regarding the associated logics of social inclusion and solidarity (e.g., welfare-workfare, burden). This part was addressed in the discussion section.

RESULTS

Schizophrenias Collective

The condition and its treatment

Both pages being sites of activism and information diffusion and exchange on schizophrenia, a major source of identity formation concerns the disorder itself, whose definition reveals significant differences between the pages (for a summary of the differences between the two pages, see Table 1). The ‘Schizophrenia collective’ circulates a typical psychiatric definition of

schizophrenia symptoms, while they refer to schizophrenia as a ‘brain disorder’, which could be a spectrum that ‘covers different disorders’, that has no known single cause and that it is rather related to an interaction of genetic and environmental factors. People with schizophrenia are referred to as ill or patients, and schizophrenia as a (mental) illness or disorder. More importantly than the definition of schizophrenia though, this page focuses on the knowledge of what people with schizophrenia *can* do and *how* this can be possible.

Individuals with capacities and hope

Beside knowledge of what schizophrenia is, posts from the ‘Schizophrenias Collective’ aim to spread knowledge and hope, that people with schizophrenia can recover, have a normal life and work, as well as the need to further develop services and projects in line with this knowledge and hope (26 posts). Therefore, this page focuses on the proposed solution which is the spreading of knowledge and practices related to the recovery paradigm, involving educational projects and psycho-social practices associated with the associations that are part of the ‘Schizophrenias Collective’.

The access and the capacity to work is a recurrent claim of this page (eight posts) and arguments include improvement of the lives of people with schizophrenia and their families, the prevention of exclusion and suicide, as well as reducing the ‘burden’ and the global costs of schizophrenia on the national economy. These arguments are accompanied by reference to laws and projects that are supposed to help people with schizophrenia find and maintain work but are not sufficiently supported in the French context. It is likewise interesting to point out that there is no description of people with schizophrenia that are not capable of working because of disability.

Thirty-eight posts use personal stories of people diagnosed and living with schizophrenia, their families, or even professionals to disseminate and support the page’s claims. A common theme among them is the encouragement to hope for the possibility of recovery and living a ‘normal’ life. Several stories concern part of the following sequence of events: appearance of the disorder, a long period of great difficulties, mostly due to the lack of sufficient services and recovery options, and then a personal discovery of the right medication, or of recovery-oriented practices and projects and finally, ‘normality’ and recovery.

It is very rare to find a narrative as breathtaking as the one of Paul. In October 2004, he spends seven days at the Hospital of Vinatier (Lyon). He talks about... his

memories from his forced hospitalization, between paranoia and feeling of omnipotence. Today, 14 years later, Paul is married and father of two kids.

In these posts one can find the same encouragement to hope for a recovery that is possible which is the main message in all shared stories, since all personal stories are stories of successful recovery, success despite the lack of recovery-oriented services or success that could have happened more easily at least, if these services existed. This encouragement to hope can also take on a rather moralizing character as in the following post:

It's better to move forward along a rocky road than to always be without hope” explains Judith, who has certainly come a long way...

Another important element underlined in such stories is the need for an active, agentic attitude towards treatment and one's condition or the presentation of such active, positive persons with schizophrenia as messages of hope. For instance, in these stories, when the lack of services and shortcomings of psychiatry are underlined, the individuals portrayed and their families facing these obstacles must find the necessary resources for future recovery on their own. More generally, individuals that manage to cope with reality in an active way are presented as examples to follow, as in the following example.

I am not a monster: Schizophrenia. That's the name which Cecilia McGough chose to give her blog. Between her studies in astronomy and her treatment for schizophrenia, she has found time despite everything to create content to raise awareness of schizophrenia among the general public and change the false way it is represented. She was invited onto the TEDx platform and gave an account of her experience of her illness...

Victims of outdated beliefs and practices

Related to this knowledge and hope for work and recovery, users are presented as victims of wrong or outdated knowledge and practice as obstacles to their recovery (41 posts). Those are lack of knowledge and erroneous beliefs regarding the disorder, outdated psychiatric practices and even lack of governmental action.

The 'Schizophrenias Collective' views stigma as erroneous beliefs about what schizophrenia is, its prognosis and how it is to be treated, held by both professionals and the public. And since the problem is lack of knowledge then in order to face stigma, one has to

improve knowledge, mostly through informing people and professionals what schizophrenia is or mostly what it isn't. Such examples concern the knowledge that schizophrenia is not a personality disorder or associated with 'split' personality, the accurate prevalence of schizophrenia in the French population. Moreover, one of the core objectives of analyzed posts concern the capacity to recover and to work. To do so, the page uses a formal style of communication, drawing on personal stories or institutional discourses and official data or even combining these argumentation resources. In the following example, the promotion of practices related to access and retention of employment for persons with schizophrenia is based on the narrative of Jérôme, who, to his surprise, was fired from his work with the agreement of his work doctor:

For people suffering from mental illnesses, stigmatization is according to the WHO 'the most important obstacle to be overcome in the community'. As Jérôme discovered to his expense, doctors can unfortunately absorb prejudices and adopt behaviors that lead to the discrimination and exclusion of patients. And yet, the position of occupational physicians could play a positive role in access to and retention of employment. One of the courses of action could be to strengthen the training of professionals who do not understand the characteristics of schizophrenia, as recently shown by *Le grand baromètre de la schizophrénie*.

Moreover, the 'Schizophrenias Collective' speaks of the insufficiency of psychiatric education, and that its services are not adequate for dealing with the difficulties faced by people with schizophrenia, or that psychiatrization should be limited. These posts, although critical of what they see as the limitations or negative aspects of psychiatry, are not anti-psychiatric, but focus on proposing ways to overcome these shortcomings which unsurprisingly evolve around recovery-oriented knowledge and practices. These posts do not support a radical change in the way mental health is thought and practiced but argue for the implementation of laws and practices that are already there but not sufficiently adopted. Likewise, the page does not present a confrontational tone towards the state and the national organization of mental health practices. Whenever the question of the 'state abandonment' of people with mental disorders appears, it is more questioned than simply affirmed and the government or the state rather seem to be recipients of recommendations for improved support of people with mental disorders than targets of confrontation.

However, one can also find critiques of stigmatizing practices or the organization of mental health services in terms of rights violation (15 posts), with issues such as the ‘state classification’ of the personal data of people involuntarily hospitalized. Psychiatry is often the target of such posts, that range from examples of behaviors of psychiatrists that did not respect the rights of patients, to a general critique of psychiatry as an institution (e.g., one post speaks of the psychiatric system that is ‘repressive and normative’ and another of hospitals that look like prisons).

A represented category

Moreover, we identified several posts that partly or entirely focus on the actions of the collective (40 posts), that aim to establish the collective’s profile as an important mental health stakeholder and interlocutor with psychiatry, the media and the state, as in the following example:

From January 2019 onwards, the Schizophrenias Collective will be part of the French Ministry for Solidarity and Health’s “*Parcours et Territorialité*” Committee. This committee will in particular be in charge of monitoring the implementation of regional mental health projects. (PTSMs).

Moreover, the page presents itself as speaking “for people with schizophrenia” and their families, or as “putting forward the voice of people affected by schizophrenia”. This representation invites though for an active stance on behalf of “patients-families-caregivers” on which as stated in the page’s description the collective “aims to make of the page ‘a place where one gets informed, but also where one finds back the joy of life, which is essential”. In nine posts the page asks the audience to share the posts in order for example to “strengthen *our* voices”, or asks audiences to “help us” or to “continue *together* the work/ efforts” etc. It places thus itself as the group’s representative, fighting for a common cause that concerns all people with schizophrenia and those around them. Finally, four posts also ask for support or even donations from the public.

The schizophrenias

An alternative framework

Compared to the previous page, ‘The schizophrenias’ provide the following explanation for their title, in more experiential/phenomenological terms:

That is to say, however, I remind you, there is not one schizophrenia, but several schizophrenias. This means that each schizophrenia is experienced differently from another. Hallucinations will always be present, but in a different way, with different senses affected. Interpretations called ‘delusions’ will also differ from person to person and from one type of schizophrenia to another.

Moreover, two posts present the disorder as the result of stress or of distress resulting from early childhood attachment problems, while other, more provocative posts, accuse western psychiatry of a normative classification of people that depicts them as socially useless, while other cultures may attribute a positive content to ‘madness’, which can also be a normal reaction to traumatic events or to the violence and oppression of the world. Thus, the main aim of 45 posts in ‘The schizophrenias’ seems to be critique-oriented knowledge, mostly providing an alternative phenomenological framework for schizophrenia, aiming to shift away from psychiatric knowledge and practices, without however being entirely anti-psychiatric. One of the main targets is medication, that is presented as potentially dangerous or ideologically associated with lack of investment on alternatives, without however suggesting that people with schizophrenia should entirely stop using it.

Attention, it is not advised to stop one’s treatment (especially immediately) without the follow-up of a psychiatrist.

Schizophrenia is characterized in terms of ‘pathology’, ‘handicap’ and there are several posts that refer to spirituality in terms of a possible resource for recovery.

Finally, nine posts try to go beyond stigma by defending or even revalorizing the group’s identity. Characteristic examples are posts that depict people with schizophrenia as people defying ‘normality’ that is presented as equal to conformism, or even posts presenting people with schizophrenia not as ill or patients, but as ‘gifted’, neuro-atypical or even people with high potential.

Victims of stigma, injustice and oppression

In this second theme, we have included 35 posts that present people with schizophrenia as victims of societal stigma, injustice, and oppression. Regarding stigma, there is a difference in

the sources identified as stigmatizing people with schizophrenia and in particular ‘The schizophrenias’ principally refer to media and the public, with no mention of stigma by professionals, contrary to the previous page. Moreover, there is also a difference in the conception of stigma put forward by these pages and in the proposed actions. ‘The schizophrenias’ consider stigma in terms of values, and in particular in terms of respect of human dignity and posts try to sensitize audiences to the equality of all human beings, the harm that negative judgement does to people with disabilities, and even propose concrete action when the media go too far. The page’s posts on stigma are generally characterized by an informal, at times emotional tone and sensitizing words such as scandal or shame.

Marseille daily newspaper scandal!!

The front page of 5 September 2017

That’s enough!!

Write to the editor; [email]

Circulate widely.

Beside stigma, a major preoccupation of this page is structural oppression and injustice, such as the current policies and practices of the state and of psychiatry. As in the previous page’s posts, one can find reference to the lack of financial resources allocated to mental health and to the indifference of the government and politicians. However, in the case of ‘The schizophrenias’, this critique towards the state and the government adopts a more confrontational or ironic and personalized tone:

Shameful. The government sentences people identified as disabled to celibacy or to being a burden for their spouse.

This last point regarding the decrease in disability pensions for people with schizophrenia is a concern for this page that also presents overmedicalization as a side-effect of the same ideology behind the lack of funding in mental health. Moreover, one can of course find posts addressing a critique on psychiatry, which again have a rather confrontational content and style, while representing psychiatry as abusive, overmedicalizing and violent and focus on the side-effects of medication.

Actors of change

As already announced at the description section of the page, the goal is peer collaboration and self-help. Therefore, the goal of the page is not representation but on the one hand, self-organization and horizontally induced change and on the other, spreading of important (peer) information on treatments and well-being. Thus, among the proposed changes is the recognition of peer professions (peer helpers), with posts presenting people with schizophrenia professionally accompanying users, recovery self-help projects and documentaries on social media platforms.

Moreover, in terms of support for the collective's posts, the page does not ask members of the audience to share their content, but calls for direct action, for instance by sharing links for petition signing against governmental decisions (e.g. pensions reform leading to "condemning people with mental disabilities to celibacy" or asking for an increase in disability pensions) or addressing media stigma by directly writing to the medium editor and to the Superior Council of the Audiovisual (*Conseil Supérieur de l'Audiovisuel*). Moreover, two other posts thank the audience for liking and following the page, for "supporting the values" of their project and ask members of the audience to join the Facebook group so they can exchange their experiences freely, and, if they are able to write and are interested, to join their project.

DISCUSSION

These results suggest that the two pages differ in their key parts of identity formation and in their attitudes towards the dominant system (see Table 1). However, they also present similarities, such as the critique of the repressive character and the inadequacy of the French psychiatric system and the lack of care on behalf of the French state, as well as a focus on the importance of stigma. Both similarities and differences can further be analyzed in terms of communication processes positioning pages and audiences *vis-à-vis* the social order. We do however acknowledge the limits of our results and our discussion of them, given the exploratory character of our study and the limited number of posts analyzed.

Table 1.

Main differences between pages-collectives on identity construction and relation to neoliberal logic

Points of difference	Schizophrenias Collective	The Schizophrenias
On schizophrenia	- Starting from a scientific approach	- Focus on experiential approach
Activism for:	- Implementation of recovery paradigm	- Provide alternative phenomenological framework

	<ul style="list-style-type: none"> - Spreading of true knowledge and tackle stigma - Spread hope that individuals can recover 	<ul style="list-style-type: none"> - Change of identity and status of people with schizophrenia - Fight stigma - Increase of disability pension
Victims of:	<ul style="list-style-type: none"> - Outdated knowledge and practices - Rights deprivation - Stigma (lack of knowledge) 	<ul style="list-style-type: none"> - Social order and systemic repression - Stigma (prejudice-discrimination)
The collective's role	<ul style="list-style-type: none"> - Represent people with schizophrenia and their families - Important actor in mental health network 	<ul style="list-style-type: none"> - Collective for direct action - Calls to join common purpose
Relation to neoliberal logic	<ul style="list-style-type: none"> - Active and hopeful subjects - Promotion of integration by work - Reducing the "burden" on national economy - Commodification of activism - Reference to lack of means by the French state 	<ul style="list-style-type: none"> - Denunciation of (neoliberal) cuts on pensions and psychiatry - Overreliance on medication related to state withdrawal

Schizophrenias Collective: *Propagation* and representational tensions

We suggest that the 'Schizophrenias Collective' follows a 'public health approach' to schizophrenia, which according to Corrigan et al. consists of an educational approach aiming to inform citizens about mental disorders (Corrigan et al., 2005). Since the end of the 20th century, this public health approach has been mainly focusing on blocked ambitions, as well as the so-called burden of mental disorders and how it can be reduced or avoided (U.S. Department of Health and Human Services, 1999). Indeed, the possibility for recovery and autonomous, productive life is one of the main goals and slogans of important public health institutions, such as the WHO and the French Ministry of Health. Thus, this page follows this 'mainstream' line, arguing for the social participation and the implementation of the recovery model in the French context, while presenting the arguments of the well-being, rights defense and the reduction of the 'burden' of mental disorders for the national economy.

Moreover, we can also find an adoption of the 'mainstream' line of thought in the definition of the disorder, that is presented as biogenetic disorder of the brain or even at the conceptualization of stigma, since for this page stigma is viewed as a lack of knowledge, something that was and still sometimes is the focus of major public health campaigns, despite the proven limitations of such a focus (Corrigan et al., 2005).

We claim that *propagation* is the communication mode of this page, that combines a rights promotion for people with schizophrenia with a dominant perspective in the way the

conceptualize the necessary change, the disorder and people that suffer from it as well as the way they position the Collective within the French mental health system. This *propagation* mode of communication is carried out with a combination of scientific evidence-based information, as well as users' narratives. Thus, the collective's proposals, actions and practices are presented as an established truth and progress in the field of mental health, contrary to lack of knowledge and outdated beliefs and practices by the public or the psychiatric field.

Hence, since the page adopts this 'public health' approach to all the above-mentioned issues, one can identify the points of contact with neoliberalism identified by previous works that characterize such an approach.

For instance, personal narratives, proposed solutions and highlighted problems focus on personal responsibility and autonomy, as well as inclusion through work, which could be an answer to the global costs or the *burden* of mental disorders, resembling what has been characterized as *workfare* rationale. On the contrary, the sometimes-unavoidable facts of dependency and disability that can characterize disorders such as schizophrenia is not given due consideration by the analyzed posts. Analysis here in terms of the *propagation* mode of communication allows us to consider in this context the presentation of personal narratives of personal responsibility, self-management and work as examples of 'positive reference' in a process of 'normative differentiation' presenting thus prototypical and exemplary individuals and behaviors within the group of people with schizophrenia. Could we also then suppose that this partial view of schizophrenia creates new 'zones' of inclusion and exclusion, of blame and shame, that are characteristic of (neo)liberal governmentality and concern passive, hopeless and non-productive subjects (Rose, 1996)?

Moreover, a comparison with the page 'The schizophrenias' reveals that while the privileged solution for social participation for the 'Schizophrenias Collective' is work, for the 'Schizophrenias' this solution is absent or rather entirely replaced by critique on reduction of disability pensions and allocations, an argument that is missing from the 'Schizophrenias Collective'. On the other hand, the problematization of mental disorders as a 'burden' for national economies is not found on any of the posts published by 'The Schizophrenias'.

Finally, according to Staerklé, *propagation* is a *strategic* mode of communication that aims to allow groups to "maintain or to extend their dominant position" and to present themselves as representatives of a social group (Staerklé, 2015). We have seen that an important part of this page's posts concerns the promotion and presentation of the collective's projects and actions, establishing thus itself as a mental health stakeholder. In this perspective, our

results show a similar pattern with previous research from within different perspectives, highlighting the struggle of health associations, groups etc. for establishing their role as an important player in the local health network (*or advocacy market?*), while adopting a public health, ‘reformist’ agenda (Rabeharisoa et al., 2014).

We should however here point out that this is not a page focusing on the dissemination of neoliberal discourses and practices, but a page actively struggling for the recognition of the rights and the social integration of people with schizophrenia. In effect, this page systematically defends the rights of people with schizophrenia, such as for instance when it accuses the French authorities of having abandoned people with mental disorders and their families, or when it speaks of the state’s stigmatizing classification of people involuntarily hospitalized or even when it attacks psychiatric practices as violent and repressive. We consider therefore that it would be theoretically sounder to speak of “representational tensions” (Kalampalikis & Apostolidis, 2016, p. 4) that encompass the page’s posts, tensions that can characterize various instances of advocacy for the rights and the social inclusion of people with mental disorders (Lampropoulos & Apostolidis, 2020).

The schizophrenias: Identity politics, human rights and *propaganda*

The posts published by this page concern oppositional, minority views in the field of mental health, that seek to fight and alter representations associated with the dominant social order (Staerklé, 2015). This strategic communication has been described as the *propaganda* mode of communication and is characteristic to minority and oppositional groups. Contestation of hegemonic views is characteristic of this mode of communication and on an intergroup level, one of the associated processes is what has been named as categorical differentiation, which consists of the assertion of a social identity that is more than simple deviance (Staerklé, 2009). Moreover, analysis in terms of *propaganda* mode allows us to identify a further difference between the two pages regarding group processes. Contrary to the Schizophrenia Collective’s efforts to establish itself as a stakeholder and a representative of people with schizophrenia, the Schizophrenias focus on creating a group that invites people with the disorder that share their views and values to join them for the continuation of their common struggle for the contestation and alteration of group and even social order representations.

One can find several examples of such contestation in the analyzed posts, contestation that is very close to what has been described as “identity politics” in the field of mental health,

namely the struggle to alter self-representations of users while “repudiating societal conceptions of disability” (Anspach, 1979, p. 765). And we have found among the posts published by ‘The schizophrenias’ some of the types of activism that were described by Anspach in terms of identity politics, such as the condemnation of the use of psychiatric drugs and revalorizing crisis as a normal response to an oppressive, traumatizing world (in line with anti-psychiatric discourses); accusations against psychiatry for its use of violent means and its views on mental illness, and a celebration of one’s identity as a reproach to normality and conformism. Anspach claims that identity politics “is a sort of phenomenological warfare, a struggle over the social meanings attached to attributes rather than an attempt to assimilate these attributes into the dominant meaning structure” (Anspach, 1979, p 765). And in our view, it is precisely this point that differentiates the activism styles of the two analyzed pages. For ‘The schizophrenias’, this struggle concerns both what schizophrenia is and how it should be treated, as well as an attack on the state that is presented as ideological, psychiatry that is presented as fundamentally violent, the media and even other associations that are presented as compliant.

Arguably, from a public health perspective, some of the content published by this page might appear scientifically inaccurate, or even potentially dangerous, leading for example to confusion as to what schizophrenia is or what its treatment should be. However, it is equally interesting to point out that the page’s contents are not anti-science, since they often try to ground their posts on scientifically presented arguments or authorities.

CONCLUSIONS

The present socio-representational exploratory study reveals the importance of studying health related phenomena in their relation to issues of ideological and normative positioning of subjects and groups. According to SR literature of illness and health, it has been suggested that among the different life consequences of illness and disorders, one can speak of the illness-profession in order to characterize the ways in which the integration of illness in one’s life implies new social relations and lifestyles (Herzlich, 2005). With the current paper, we propose that such conceptualization necessarily must account for the positioning of individuals and groups in the social edifice and our results highlight the representational tensions and points of contact or conflict regarding the neoliberal logic and ethos. We therefore call for the further study of the ways this positioning can be communicated, legitimized, negotiated, or even contested.

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