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While producers of the DSM argue that psychiatric diagnoses are real entities (taxon), they are vague and abstract constructs that lack conceptual boundaries and remain heavily influenced by socio-political realities.[1] Consequently, it can be argued that the DSM as a “scientific” instrument is an oxymoron: “the DSM has little to do with science, its content is determined primarily by the gatekeeping efforts of the small number of influential psychiatrists who have the directive to decide which disorders will be allowed to appear and which will not”. [2 p179] In fact, it is the product of individuals who chair committees and who vote on the inclusion or exclusion of certain diagnostic groups.[3,4] According to Kirk and Kutchins, “to a great extent psychiatric nosology has been a product of committee meetings and smiling faces”, [5 p29], where psychiatric nosology is not so much about addressing construct validity as it is seeking to address face validity: professional consensus. It is also important to highlight that strong financial ties currently bind the developers of the DSM with pharmaceutical and other companies who are powerful drivers of the psychiatric system.[6]

The construction of mental illness is now largely based on the assumptions that physiological, genetic, and/or chemical abnormalities are at the roots of behavioural deviance.[7] The hypothetical association between mental illness and the lack or excess of neurotransmitters justifies the need to develop molecules meant to restore balance in individuals’ brains.[3] In other words, the multiple sites of therapeutic action in the brain are at the heart of modern psychiatry.[8] However, the biological classification of mental disorders serves purposes other than clinical. A significant outcome of the DSM-III is the growing association between its classification scheme of mental disorders, insurance coverage of mental “care”, [9,10] and the rising numbers of chemical compounds produced by pharmaceutical companies--a phenomenon that remains controversial in light of the fifth edition of the DSM. These relationships form a dense web, a medical-industrial complex whose members have much to gain financially from additional diagnostic categories. The rise of biopsychiatry and the concomitant expansion of classification schemes are of great interest to pharmaceutical corporations whose business objective lies in the production of drugs that target neurotransmitters’ functions in the brain. Pharmaceutical companies are pivotal funding agencies in the promotion, development, and dissemination of (bio)psychiatric research. They therefore constitute powerful instigators (and beneficiaries) of the fabrication of new psychiatric labels.[11] Along with Kutchins and Kirk,[9] we therefore

contend that the unlabelled masses of individuals in today's societies represent an untapped resource for the economic growth of corporations, such as pharmaceutical industries, who are heavily involved in the "psychiatric business."

The entire text is a shorten version of Introduction in Holmes, D., Jacob, JD., and Perron, A. (2014). Power and the Psychiatric Apparatus. Ashgate: Surrey.

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Abstract

Drawing on a situational analysis of a recent anti-stigma campaign in psychiatry (*Defeat Denial: Help Defeat Mental Illness*) this paper seeks to engage with the reader on the use of an expert discourse that focuses on the brain and its disruption as a way to address stigma associated with mental illness. To begin, we briefly highlight key statistics regarding the impact of mental illness in Canada and introduce the concept of stigma. We then introduce the *Defeat Denial* media campaign and describe the analytical process employed for this paper - Situational Analysis with a specific focus on discourse. We then expand on the use of the expert discourse in the awareness campaign by making connections with Rose's concept of biological citizen and, in the final sections, present recent studies on stigma that highlight the paradox and contested construction of the (bio)psychiatric self.

Key Words biopsychiatry, mental illness, public health campaigns, stigma

Exposing the Expert Discourse in Psychiatry: A Critical Analysis of an Anti-Stigma/Mental Illness Awareness Campaign

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Introduction

Over the last two decades, public health initiatives to address both the burden of mental illness and its associated stigma have gained significant momentum.[1] In parallel with the growing realization that people with mental illnesses suffer from both their disorders and the stigma that accompanies them,[2] we have witnessed the deployment of initiatives that seek to diminish both their occurrences and impacts. Of particular interest for this paper are the ways in which mental illness information is conveyed to the public in

the form of mass media awareness campaigns and, more specifically, the ways in which these messages seek to brand the issue of stigma related to mental illness.

We recently engaged in the examination of a public health campaign produced by the Centre for Addiction and Mental Health (CAMH) in Toronto (Ontario, Canada) aimed at enhancing mental illness awareness and combating stigma both at the individual and societal levels. In so doing, our objective was to critically examine the 2012 awareness campaign *Defeat Denial*[3] and make explicit the discourses embedded in the campaign. Drawing upon this research, this paper seeks to engage with the reader on the use of an expert discourse that focuses on the brain and its disruption as a way to address stigma associated with mental illness. To begin, we briefly highlight key statistics regarding the impact of mental illness in Canada and introduce the concept of stigma. We then introduce the *Defeat Denial* media campaign and describe the analytical process employed for this paper - Situational Analysis with as a specific focus on discourse.[4] We then expand on the use of the expert

discourse in the awareness campaign by making connections with Rose's concept of "biological citizen"[5] and in the final sections, present recent studies on stigma that highlight the paradox and contested construction of the (bio)psychiatric self.

Mental illness and stigma

With an unprecedented impact on health, mental illness leaves no segment of Canadian society unaffected. It is estimated that 3% of the Canadian population experience serious mental illness and 17% experience mild to moderate mental illness.[6] In 2011, 5.6% of Canadians over the age of 12 perceived their mental health as fair or poor.[7] According to the Mental Health Commission of Canada,[8] seven million Canadians will need help for mental health concerns each year, and every day, 500,000 Canadians miss work due to psychiatric reasons. Dewa et al.[9] estimate the economic burden of mental illness and addiction in Canada to be \$51 billion annually.

Compounding these findings is the impact of stigma attached to mental illness. It is estimated that 60% of people with a mental health problem or illness will not seek help for fear of being labeled.[8] According to the Ontario Ministry of Health and Long Term Care, the public is more inclined now than it was "a few decades ago to perceive people with mental illness as dangerous".[10 p41] The stigma associated with mental illness and addiction is often based on misconceptions such as: the association between mental illness and violence; mental illness is a single, rare disorder; people with mental illness or addiction are poor and less intelligent; and, mental illness or addiction is caused by a personal weakness (Mental Health Commission of Canada, as cited by Ontario Ministry of Health and Long Term Care.[10 p41] It follows that people with a mental illness often describe the associated stigma as more life-limiting and disabling than the illness itself.[8]

Conceptualizations of stigma often build upon the work of Goffman[11] that defines "stigma as "an attribute that is significantly discrediting" and that serves, in the eyes of society, to reduce the person who possesses it".[12 p14] According to Link and Phelan,[13] what is most important in identifying the meaning of stigma is the culturally mediated and temporally located relation between the attribute and a stereotype. In effect, these authors recognize the centrality of individual perceptions as well as the consequences that these perceptions have on social interactions. However, they reframe the notion of stigma as a social process that can only be understood in relation to broader notions of power imbalances inherent in stigmatization. According to

these authors, stigma occurs when the following interrelated components converge: people distinguish and label human differences; dominant cultural beliefs link labeled persons to undesirable characteristics (negative stereotypes); labeled persons are placed in distinct categories so as to accomplish some degree of separation of "us" from "them"; labeled persons experience status loss and discrimination that lead to unequal outcomes. Link and Phelan[13] thus highlight that inherent to stigma is the exercise of power, whereby "stigmatization is entirely contingent on access to social, economic, and political power that allows the identification of differentness, the construction of stereotypes, the separation of labeled persons into distinct categories, and the full execution of disapproval, rejection, exclusion, and discrimination".[13 p367] Adding to this, the World Health Organization[14] suggests a broader relationship between misinformation and stigma:

"Politicians and the general public are only partly aware of the fact that effective treatment of most mental disorders is possible. The image of mental illness is contaminated with images of violence, sin and laziness. Most health workers are not conversant with modern methods of treatment of mental illness and often do not possess the necessary skills to deal with it. Among them there are many who believe that the only way of dealing with mental illness is long term hospital care. In the majority of countries, including developed ones, there is no parity of care for mental and physical illnesses. Stigma of mental illness gains strength from these misconceptions and reinforces them."

Although it is important to contextualize the situations in which stigma occurs, it is also important to understand how stereotypical views and categories (often portrayed in the forms of labels), as sources of information, shape interactions with oneself and with others. According to Link and Phelan,[13 p369] categories and stereotypes are often "automatic" and facilitate "cognitive efficiency". The automatic nature of this thought process is revealed in research indicating that categories and stereotypes are used in making rapid judgments and thus appear to be operating preconsciously.[13] What makes these elements dangerous is the inherent lack of critique that labels imply and the automatic images that they can create in a person's mind.[15] For example, labelling mental illness as a disruption in brain circuitry (as explored in this paper) is a label that refers to a set of preconceived understanding regarding the ontology of behaviours thus indicating how we should expect mentally ill people to behave in light of a specific diagnosis. Concurrently, this label will likely influence how we interact with the labelled individual because of the label's implicit assumptions. That is, labels create virtual lines

of differentiation[11] representing a particular process of classification which will likely shape the social identity of the labelled individual and their social interactions with others in a particular context. Indeed, people who are labelled as mentally ill may act less confidently and more defensively, or they may simply avoid a potentially threatening contact altogether.[13] As further described and researched by Link and Phelan[13 p374] in their literature review, “the result may be strained and uncomfortable social interactions with potential stigmatizers (Farina et al., 1968), more constricted social networks (Link et al., 1989), a compromised quality of life (Rosenfield, 1997), low self-esteem (Wright et al., 2000), depressive symptoms (Link et al., 1997), unemployment and income loss (Link and Phelan, 1982, 1987)”.

The public awareness campaign: “Defeat Denial”

The Centre for Addiction and Mental Health (CAMH) is a large Canadian mental health and addiction teaching hospital and a research centre in the area of addiction and mental health. CAMH launched the first stage of the three-part *Defeat Denial* campaign in June 2012.[3] The campaign began with an initial promotion in transit shelters in late May 2012, in which CAMH was not named. Centered in the Greater Toronto Area, the campaign formally began in early June 2012 with advertisement spots in theatres, a Toronto Star Special CAMH section on June 9, as well as billboard, subway, radio, newspaper and online advertisements. In the aim of encouraging a broader public conversation related to its objectives, the campaign included an interactive online component, through the social networking sites Facebook and Twitter as well as through a website dedicated to the *Defeat Denial* campaign. The first stage of the campaign ended in July 2012. The second stage, described as “informed by the conversation generated in the first stage”, was scheduled for mid-September to mid-October 2012 and included a video contest. Although the launch of the third stage was scheduled for early 2013, it had not yet occurred at the time of drafting this article in May 2014.

The *Defeat Denial* campaign aimed to challenge the stigma associated with mental illness by compelling “people to rethink their perceptions of mental illness and addiction,”[3] as well as raise awareness about the work of CAMH. It follows that the stated objectives of the campaign were to, “raise public consciousness about mental illness as an issue which needs to be addressed on both a personal and societal level,”[3] and “increase public awareness of CAMH as a leading teaching hospital and research centre, and about our vision for social change”. [3] The familiar clichés used as

the feature of the campaign messages were developed by an advisement company and aimed to be both relatable and to provoke self-reflection and change.

The first two stages of the campaign included twenty-six print ads (as found on the *Defeat Denial* website) placed in newspapers, magazines and bus shelters. Of these ads, two were in Spanish and two were in Chinese. The text-based advertisements have a simple, uncluttered appearance and each is depicted in only white and either soft purple, green, blue or orange. The upper half to two thirds of each ad features a phrase representing a cliché or stereotyped/dismissive message commonly expressed to people purportedly struggling with mental illness. The clichéd phrases appear in a large font, framed with quotation marks and canvassed on white. In some of the advertisements, only the cliché phrase appears while in others, a response, a question or a short counterpoint is offered in smaller font below the prominent cliché. In two of the advertisements, several paragraphs of text appear and serve to inform a significant part of the present analysis. The phrases “Defeat Denial. Help Defeat Mental Illness.” and the CAMH logo appear in the bottom right corner while Facebook and Twitter logos appear in the bottom left corner of each ad. The following message is an example of the ads presented in the campaign that were used for the current analysis. All other posters are available on the campaign’s website.

Dismissive Message: “It’s all in your head.”

Additional text: “Or as we’re discovering, your brain. It’s ironic that one of the phrases people use to dismiss a mental illness actually contains more insight than you might think. Because many mental illnesses are the result of things that actually happen in your head – like disruptions in brain circuitry. By understanding the brain better, we’ll be able to make huge advances in early detection, diagnosis and treatment. How important is this? Important enough that \$30 million has just been donated to CAMH for next generation brain science research. Our work will attract the world’s leading scientists and clinicians and CAMH will be a beacon to mental health experts around the globe. By deepening people’s understanding of the brain and the science behind mental illness, we hope to overcome the stigma and prejudice. Because if we truly want to transform lives, we must also transform the way society thinks about mental illness.”

The *Defeat Denial* campaign was part of CAMH’s Strategic Plan entitled VISION 2020,[16] which was also launched in June 2012. The plan, comprised of six strategic directions, included “Drive social change,” under which the campaign falls. This direction orients CAMH to “advocate with sensitivity and impact,” “respond to mental health priorities in our environment,” and build “public awareness of mental illness and addiction.” The direction is one that engages the

organization to transform “society’s understanding of and attitudes toward mental illness and addiction” and to “fight against prejudice and discrimination.”

The campaign is situated in the broader Canadian context, in which one can identify a growing movement to transform societal perceptions related to mental health and illness. The formal inception of this trend can be traced to 2006, when the Standing Senate Committee on Social Affairs, Science and Technology completed a national review of mental health and addiction services in Canada. This marked the first and most extensive analysis of the Canadian mental health system and a key finding delivered in the Committee’s final report, *Out of the Shadows at Last: Transforming Mental Health, Mental Illness and Addiction Services in Canada*,^[6] was the lack of national focus for mental health issues in Canada. The Committee recommended the creation of the Mental Health Commission of Canada (MHCC), which would be tasked with, among other things, the delivery of a ten-year anti-stigma program. This program took the shape of Opening Minds, established by the MHCC in 2009. Working with service providers, communities and people with mental illness and their family supports, the program targets health care professionals, youth, the workforce and the news media as its focus areas for reducing stigma related to mental illness and for cultivating an environment in which those living with mental illness feel comfortable seeking help, treatment and support.^[8] A central operating tenet of the Opening Minds initiative has been to “identify, document, and disseminate best practices in stigma-reduction using networks of existing programs as community leaders”.^[8] This analysis can be situated in the effort to examine the present stigma-reduction effort to ultimately contribute to this evolving movement.

In the same vein, the *Defeat Denial* campaign can be situated in the broader provincial political and financial context. The 2009 Ontario government discussion paper, *Every Door is the Right Door – Towards a 10-Year Mental Health and Addictions Strategy*,^[10] identified stopping stigma as a key direction. Followed by the launch of *Open Minds, Healthy Minds – Ontario’s Comprehensive Mental Health and Addictions Strategy*^[17] in June 2011, this strategy, focused on children and youth, paralleled new funding commitments taken by the Ontario government in the area of mental health. Among the goals of the strategy was to create healthy, resilient and inclusive communities with an expected result of less stigma and discrimination in public services and in the workplace. Specifically, the Ontario government pledged to:

- Implement more mental health promotion and anti-stigma practices for children and youth, educators, health providers,

workplaces, seniors’ service providers, municipal service providers, justice providers and the public;

- Acknowledge that mental health and addictions services should reflect Ontario’s diversity, and take steps to achieve this.^[17]

Should the campaign have unfolded as initially scheduled, it would have only marginally preceded the publication of the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)* in May 2013. This contextual detail is significant to the extent that the *DSM* does, in some respect, guide the way mental disorders are conceptualized. In this case, the expansion of diagnoses proposed for the *DSM-5* did not go without opposition from academics, clinicians, etc. as the question of its scientific and objective claims were (once again) publicly debated.

Situational analysis: Critical mapping as research methodology

Situational analysis is a research method that seeks to expose complexity by way of “elucidating the key elements, immaterialities, discourses, structures and conditions that characterized the situation of inquiry”.^[4 p.xxii] Informed by the work of Clarke (2005),^[4] this research method lends itself particularly well to critical research projects ^[4, p.78] and has proven to be particularly useful in “exploring the often fleeting/shifting discourses and conditions existing within [specific contexts]”,^[18, p.299] “turning up the volume of lesser but still present discourses in a situation”,^[19 p130] and “allowing mute evidences to be heard”.^[20 p131] The strength of this method is based on the construction of various maps (situational maps, social world/arenas maps, positional maps) that enable researchers to examine a given situation in all of its complexity by “generating the kinds of data in which we can find often invisible issues and silences”.^[4 p76] According to Clarke,^[4 p.xxii] these cartographic exercises or maps, used alone or as part of a larger methodology (i.e. grounded theory), help situate research projects “individually, collectively, organizationally, institutionally, temporally, geographically, materially, discursively, culturally, symbolically, visually, and historically”. In other words, this method enables researchers to draw from various data to make explicit the complexities at play in a situation and help understand its meaning(s), problematize its effect, etc. For the purpose of this paper, we used Clarke’s cartographic exercises as the principal analytic method as it offered a creative and structured analytical process. More precisely, we focused primarily on the creation of situational maps (both disorganized and organized) to engage in a relational

analysis and highlight the various discourses at play in the campaign. The method (mapping and relational exercise) will be described in the next section of the paper.

Despite being a campaign that was highly “visible”, the main aspects used in the analysis were in the form of text (as opposed to other mapping exercises that may have included pictures or videos). In this sense, analyzing text through situational mapping enabled us to tease out various discourses related to the situation of interest and, in the process, draw close attention to power dynamics that are embedded in the campaign messages. For the purpose of explanation, we must understand this undertaking as a form of critical discourse analysis; that is, a type of analysis that examines written text in search of elements that both produce and re-produce power relations that may not always be overtly evident.[4] Anchored in Foucauldian thought, critical discourse analysis can, therefore, be understood as a way to unveil the hidden politics embedded in the text which seek to reinforce the status quo (dominant discourse). In this sense, a given discourse “not only sets limits and restricts that which can be said about a phenomenon”, but also “empowers certain agents to speak and make representations, while also disempowering others from doing so”. [4 p160] As such, we understand a discourse as a set of statements that embody “the historically specific relations between disciplines (defined as bodies of knowledge) and disciplinary practices (forms of social control and social possibility)”; [21 p26] That is, “in any given historical period we can write, speak or think about a given social object or practice (madness, for example) only in certain specific ways and not others. ‘A discourse’ would then be whatever constrains – but also enables – writing, speaking, and thinking within such specific historical limits”. [21 p31] If we look at the awareness campaign as something that is part of a discourse about mental illness, what then is said about mental illness? What discourse(s) can be identified, how does it “constrain” the way mental illness is perceived and, in the process, come to shape what it means to be (ab)normal? As Rudge, Holmes, and Perron [22] argue, turning to a critical discourse analysis enables a closer look at the elements that structure and are structuring debates over truth(s).

The way in which the campaign attempts to defeat stigma related to mental illness—that is, through the references to internal (biological) disruption—encouraged us to critically examine the words displayed in the ads, to map the discourse practices involved in the production and interpretation of the messages featured in this campaign, and to situate the campaign within a much broader social context. Based

on our analysis, we argue that using a bio-psychiatric framework to challenge individual and societal stigma ought to be challenged in light of its individual and collective implications (effects). In the following segment, we will expand on the use of the expert discourse in the awareness campaign and its possible stigmatizing effects. As such, we will examine how such a campaign contributes to a broader discursive production of otherness using current literature on stigma. Although the ensuing analysis is the result of a rigorous analytic process, it remains influenced by the researchers’ paradigmatic position and theoretical sensitivity as well as the chosen material of study.

Research method: Mapping the campaign

Our objective in this paper was to critically examine CAMH’s awareness campaign along with the discourse materials located and collected for the project. In order to explore the discursive body of the campaign, we turned to important documents produced by governmental bodies as well as leading organizations in mental health at both the provincial and national levels. We also reviewed epidemiological data on mental illness and scholarly publications in the field of mental health and stigma. Finally, we chose the campaign’s web based advertisements as the primary discursive terrain for analysis.

Using the cartographic exercises proposed by Clarke, [4 p187-8] we critically examined the awareness campaign (situation of inquiry) using a cluster of key questions:

What are the discourses in the broader situation? Who (individually and collectively) is involved (supportive, opposed, providing knowledge, materials, money, what else?) in producing these discourses? What and who do these discourses construct? How? What and whom are they in dialogue with/about? What and who do these discourses render invisible? How? What material things – nonhuman elements – are involved in the discourses? What are the implicated/silent actors/actants? What were the important discursively constructed elements in the situation? What work do these discourses do in the world? What are some of the contested issues in the discourses?

Based on these questions, we created a disorganized situational map to identify all the analytically pertinent elements within the situation of inquiry (messy map). Following this brainstorm exercise, we displayed each element onto an organized situational map using the categories provided by Clarke. [4 p193] That is, the elements identified in the disorganized map were regrouped into categories to start drawing links between these elements and, in the process, engaging in the analysis of the data. As such, creating the organized map allowed us to situate the

awareness campaign within a particular political context. We noted that the campaign was part of broader governmental and cause marketing strategy to diminish stigma associated with mental illness but was also a branding exercise for the CAMH organization.

As with other public health campaigns, we can locate the present campaign within a governmentality framework, since it deals directly with the management of a population.[23] Governmentality, a term coined by Foucault,[24] can be understood as society's general mechanisms of governance in that it is concerned with those practices that try to shape the beliefs and the conducts of a population – practices that are deeply embedded within a network of power relations which cannot be reduced to the state and its official institutions. [25] According to Foucault,[24] governmentality relies on a specific security apparatus in the government of conducts. Contained within this apparatus of security are public health campaigns since they play an important role in maintaining social order.[23] That is, governmentality is ensured by specific forms of knowledge (e.g., scientific), which in turn permit the establishment of norms, serve as the basis for the development of expert discourses, and are used to penetrate

the capillaries of society by attempting to shape individual conducts in various ways.[26] In the interest of health, the CAMH campaign seeks to address the growing public health threat of mental illness – it seeks to force a review of how we think and act regarding mental illness in order to facilitate access to proper treatment, by establishing proper forms of interactions and capitalizing on the conformity and rationality of each member of that population.[23]

The campaign can also be situated within the logics of the free market, where consumption of psychiatric services is based on brand image in order to “sell” mental illness and mental health services. In analysing the *Defeat Denial* campaign, there is a clear emphasis on communicating a branded health message, one that positions mental health as an issue that transcends any one advertisement. That is, “[b]rands position their objects in the lives of consumers in the larger social and physical environment in which we live”. [27 p722] For example, the biopsychiatric understanding of mental illness, as well as its reference to scientific progress, helps create a social norm with regards to mental illness as a disorder that finds its origins in malfunctioning brain circuitry. This norm thus contributes to creating a social

Table 1: Major Discourses

Epidemiological	Referring to the use of statistics as an objective representation of mental illness (prevalence of the problem).
Scientific/technological	Referring to the use of the term “science” and its superlatives (ex. next generation brain science) to give authority to the campaign, explain and validate the work that is being done and support the claims made in the posters.
Biopsychiatric	Referring to the construction of mental disorders as biological disorders thus framing our understanding of mental disorders and positioning the brain as the site of investigation. Ex. References to brain circuitry as somehow “disrupted”.
Economical	Referring to the links made between mental health and its effects on productivity but also highlighting the importance associated to mental health issues (research funding).
Therapeutic/altruistic	Referring to language that claims to be supportive, caring, motivating, accessible, understanding, etc.
Normalizing	Referring to elements in the posters that establish or make reference to some form of standard - the consumption of mental health services (notably hospital services); mental illness has to do with disruption in the brain; being free from mental illness and the link to productivity (going to work), etc.
Chronicity	Referring to the emphasis placed on the brain and the need to acknowledge that mental illness can last a lifetime.
Promotional	Referring to the action of promoting certain behaviour as well as the work of the organization (branding).
Emotional	Referring to the emotional impact of the campaign itself (shock) including effects such as: shame, guilt in seeing how we dismiss mental health issues, but also the hope that new scientific discoveries will bring to our understanding of mental illness.

environment in which understanding mental illness as a brain disorder becomes the gold standard and informs future research and treatment. In this case, branding can be seen as a biopolitical strategy in that it is evaluated on the “formation of associations between the individuals exposed to branded health messages and adoption of health behaviours”. [27 p722] Understanding mental illness as a brain disorder materializes the messages found in the campaign – mental illness is very real and has a devastating impact – and should not be dismissed. In this case, CAMH’s references to objectivity through the language of science and inclusion of individual experiences of people who live with mental illness enable them to represent themselves as ethical and responsible actors in the battle against stigma and the denial of mental illness. Amidst the scientific discourse of the campaign, however, is the lack of critique that it implies. As with Jenkins, [28] we are conscious of the multiple forces shaping our understandings of ‘mental illness’ and cannot ethically rely on an oversimplified biomedical view, one that has come to gain hegemony in healthcare to tackle what some consider to be societal problems. In other words, the mapping exercise used to analyze the campaign enabled us to draw a close attention to the politics of knowledge at play within the text and reinforced the need to look at those other ways of understanding mental illness that remained silent in the campaign.

The map also demonstrated how the campaign highlighted the negative ‘impact’ of the illness by playing up its chronic, debilitating effects to rationalize the incongruence of dismissive attitudes towards people with mental illness. In fact, we noted that the statistical data utilized in the campaign was a key element in the elaboration of the prevention campaign, in that it highlighted (made visible) the harsh ‘reality’ of mental illness and the need to acknowledge it; but it also offered a structure to promote CAMH’s (bio) psychiatric research by framing it within an ethos of hope and humanized care – a subject that we will revisit later on in the paper. The most important feature of the organized map was the identification and reorganization of the major discourses related to the situation of inquiry (see Table 1 for a list of major discourses identified in the situation of inquiry).

After examining each discourse within the situation of inquiry (awareness campaign) and organizing/analysing the disorganized map, we chose to focus on the expert discourse as a way to create a space for critique. This decision was the starting point of another analytical exercise (relational analysis), which was conducted to investigate the relationship between the expert discourse and numerous elements

contained in the situational map (including other major discourses). By making connections on paper (returning to the disorganized map and using a the expert discourse as the center of the relational exercise) we reiterated the inherent assumptions of the campaign whereby dismissive messages are associated to a lack of knowledge about mental illness on the part of the public resulting in a lack of consumption of mental health services by those considered to be suffering from a mental illness (2/3 of people suffer in silence). Here, ‘shock’ is considered to be the best way to increase awareness of the effects of mental illness in the general population, but also to solidify the psychiatric expertise at play in the campaign and to change individual attitudes and behaviours. From this perspective, the difficulty in recognizing mental health issues in fellow human beings and the subsequent use of dismissive messages is represented as an unwanted behaviour which takes place when we (the general public) lack proper understandings of mental illness. In the campaign, the consequences of mental illness are very real (possibly chronic and disabling) and affect a relatively large number of Canadians. The public lack of sensitivity/knowledge regarding mental illness, therefore, can be understood as a prerequisite for the consumption of “shock” messages and, subsequently, the self-realisation of deviant behaviour and uptake of a prescribed social norm such as the recognition of mental illness in fellow human beings and the consumption of mental health services. In this sense, the stigma associated with mental health and the associated dismissive messages are used to construct meaning around mental illness, but also disseminating a certain normalized message that (re)repositions the psychiatric institution as a place of care, understanding, knowledge and scientific innovation. In other words, it is not only the stigma of mental illness that is addressed in the campaign, but also the stigma of psychiatry in general that is targeted.

In this case, mental illness is described within a linear, decontextualized, biopsychiatric model – one that is presented as a rational action to deal with mental health issue and that remains silent on the context in which mental health issues arise since the individual body is represented as the site of disease in need of social recognition. It is the defective brain and, by extension, the individual body that is the locus of otherness. If the campaign aspired to help the public understand human diversity, recognise suffering and foster change in attitudes, it nonetheless reduced human experiences to a common feature: that there exists a certain normal brain circuitry and that mental illness results from its disruption.

Based on our analysis, the awareness campaign is inherently political because it is deployed by an organization with the clear objective of both penetrating the collective and personal domains to manage/govern the population and their individual behaviours, thoughts, etc; but also promoting their own agenda as an organization. Unsurprisingly, then, the use of these messages to which we should identify with are perceived as an effective strategy to create a state of discomfort, but also to shape the way we come to understand what mental illness is. In the following segment, we expand on the use of the expert discourse in the awareness campaign by making connections with Rose's concept of the "biological citizen"[5] and Foucault's concepts of subjectification and power-knowledge dynamics.

Expert discourse

According to Rose,[5] there is a recent shift in the way human life is understood. If for the greater part of the 19th century scientists and lay people have focused on "the visible, tangible body",[5 p11] we, as a collective, seem to be entering an era that is marked by an intensification of what can be seen. We now speak of another type of visibility and understanding, one that takes place at the molecular level. As such, we are witnessing a shift in the way health and therapeutic successes are conceived, in that they are implicitly framed in molecular parameters.[30] This shift also implies a certain loss of agency in those who feel unhealthy in that subjective experiences of health are now reinterpreted in light of so-called objective/observable measures. This reinterpretation is, in part, the purview of those who claim to have some form of somatic expertise which becomes the vehicle of truth about one's health-illness experience. As Jacob and colleagues argue,[29] the expert medical discourse exerts a considerable control over the perceptions of one's experience with illness, therapy and more importantly, one's body and emotions. The campaign, for example, by focusing on the brain, acts as a medium through which the expert discourse fosters a (bio) psychiatric translation of individual illness experiences, thus silencing other forms of understandings (knowledge).

Here, Rose[5] speaks of a new style of thought and argues that with it comes new ways in which human beings will come to experience themselves as biological selves, but also shapes new forms of government and expertise. As with Rose,[5] we understand this molecular style of thought as "a particular way of thinking, seeing, and practicing. It involves formulating statements that are only possible and intelligible within that way of thinking. [...] A style of thought is not just about a certain form of explanation, about what it is to

explain, it is also about what there is to explain. That is to say, it shapes and establishes the very object of explanation, the set of problems, issues, phenomena that an explanation is attempting to account for".[5 p12] If we take for example the issue of mental illness, a new molecular style of thought opens the way for a whole new variety of explanations that reside within the molecular structure of the brain. In that process, other ways of looking at the phenomenon of mental illness are marginalized. As with Jenkins,[28] we understand this marginalization to be a symptom of contemporary politics of knowledge where scientific (read objective and experimental) knowledge has achieved a form of elite status and is considered to be an ideal necessary for societal progress. In this case, the 'science' promoted in the campaign is one that is closely linked with a biomedical view of mental illness. In effect, the somatic expertise that is presented in the campaign is central to the truth discourse about mental illness. In the campaign, we can appreciate how the centrality of the brain (and its malfunction) becomes fertile ground for novel forms of regulatory strategies. Here, it is not so much the responsabilization of individuals in managing their brains to stay healthy that is at stake,[30] but rather our responsibility as good citizen towards others by conceptualizing mental illness as a disorder of the brain and increasing our capacity to recognize it.

As indicated earlier in the paper, the structure of the campaign facilitated the promotion of CAMH's (bio)psychiatric research by framing fears and anxieties associated with mental illness within an ethos of hope and humanized care. Known as ethopolitics, this technique seeks to "shape the conduct of human beings by acting upon their sentiments, beliefs and values".[5] Here, Rose speaks of how people come to see themselves as biological selves, and will evaluate and act upon themselves in terms of this belief in what we understand to be a process of subjectification. The campaign is, in some respect, geared in this this manner, where people are shocked by the 'effects' of mental illness as well as its dismissive messages, and should engage in a reflection which would eventually lead to an implicit reconceptualization of mental illness as a brain disorder. That is, the biomedical view offers a logical, sanitized explanation of mental illness, but it also narrows the possibilities to deal with this issue by framing the way we permit ourselves to see, act, and feel towards mental illness. In its attempts to normalise mental illness and eradicate stigma, the campaign reinforces biomedical hegemony which grants certain experts exclusive rights to speak and act, relegating other ways of conceptualizing the issue as invisible influences.

Moving beyond the expert discourse: Expanding on the (bio)psychiatric roots of stigma

In this section, we consider the claims of anti-stigma proposed by the campaign as they (the claims of the campaign) focus on the brain and attempt to normalise the experience of mental illness. Literature on stigma unearths the potential (negative) effects that may follow such a campaign. As with Phelan,[2] it is possible to appreciate the hope that is associated with the biological understandings of mental illness but nonetheless remain skeptical on its de-stigmatizing properties. In the campaign, the bio-psychiatric discourse is played-up and portrayed as a possible solution to reduce stigma—i.e., that current understandings of the brain through science will lead to such an outcome. Despite the undoubtedly good intentions of the campaign, it is puzzling to appreciate why an anti-stigma campaign would centre on the biology of mental disorders given that “evidence actually shows that anti-stigma campaigns emphasizing the biological nature of mental illness have not been effective, and have often made the problem worse”. [31 p190] As Read, Halsam and Magliano [32 p158] argue:

[t]he core assumption of most anti-stigma programmes is that the public should be taught to recognize the problems in question as illnesses or disease, and to believe that they are caused by biological factors like chemical imbalance, brain disease and genetic heredity. The thinking behind this well intentioned ‘mental illness is an illness like any other’ approach is that if we can’t control our behavior, we can’t be held responsible and, therefore, can’t be blamed. It is the ‘mad not bad’ argument, with the mad part portrayed as biologically based illnesses.

The campaign is not unlike previous public health efforts to increase our mental health literacy; that is, increase the “knowledge and beliefs about mental disorder which aid their recognition, management and prevention”. [31 p159] As with the current campaign, we are ‘literate’ if we ‘understand’ that mental illness is very real, potentially chronic, and may be devastating; that we can ‘recognize’ behaviours as examples of a particular psychiatric illness and as a result, modify our own attitudes and behaviours towards those who experience them because we ‘know’ that, for the most part, they are caused by a disruption in brain circuitry and arguably, that we ‘believe’ in treatment using psychiatric drugs. [31]

Thus, mental health literacy is, in large part, framed within a particular discourse about mental illness – one based on a biological/essentialist understanding of its causes. According to CAMH’s 2012-2013 annual report, 74% “of Ontarians surveyed who saw CAMH’s *Defeat Denial* awareness campaign reported changed attitudes toward mental health”.

[33 p24] We wonder, in this case, if the change in attitudes has more to do with the uptake of mental illness as a brain-based illness, rather than as a real change in publicly-held attitudes towards those living with mental illness. We can understand here how the campaign describes success, in that a high level of mental health literacy, in this case, is a measure of the capacity to shape the way people see mental illness – regardless of its actual “anti-stigma” effects in terms of behaviours towards people with mental illness. The challenge in this situation, and in light of the scientific reference that is promoted in the campaign, is to question whether there is another way to understand mental illness—one that does not hold the bio-psychiatric discourse as the only ‘truth’ about mental illness. In effect, studies consistently show that emphasizing the psychosocial origins of mental illness are more likely to affect attitudes positively whereas emphasizing the biological understandings of mental illness do just the opposite. [31]

The campaign must, therefore, be considered as an attempt to improve our ‘mental health literacy’ by increasing the ‘evidence-based’ knowledge that positioned mental illness as a brain (biologically) based illness, and, arguably, strengthen the traditional link between medicine and pharmacological treatment. As with Read et al., [31] we concur that campaigns promoting such a message are far from being evidence-based, especially when linking biological origins of mental illness to reduction in stigma. In this case, using a biological explanation (disrupted brain circuitry) as the root cause of mental illness only accentuates the burden of disease by situating the problem within the person, rather than to engage in the difficult task of addressing the contextual elements that may be at the source of the problem. As Read and colleagues argue, [31] turning up the volume on biopsychiatry reinforces an essentialist view of mental illness—one often associated with an increased social distance, a poor view on recovery, and a perspective that (re)produces stigmatic behaviour. This is not to say that biopsychiatric research is not important. Much to the contrary, biopsychiatric research is important as it remains one way to produce knowledge. Nevertheless, we need to be cautious not to mistake research endeavours for “truth” about mental illness – especially when it is established that addressing social issues (e.g., housing) have as much of an impact on mental health, if not greater, than other biological interventions. According to Jenkins, the “hegemony of biomedical knowledge within healthcare research and practice comes at a cost” in which “other mechanisms underlying illness and disease, such as social, economic or psychological factors, are

not adequately explored or attended to”.[28 p2] As such, the biologicalization of mental illness “diverts attention and resources away from social, political and spiritual understandings of distress and is testimony to the power of [bio]psychiatry to create subjectivities”.[34, p.84] To remain uncritical about such campaigns is to understand that it not only acts upon us in trying to change our behaviours, but also through us. What we think we know about mental illness shapes how we understand ourselves as human beings—to cast a narrow view is to dangerously constrain possibilities for understanding, action and subjectivity.

Final remarks

The language of brain circuits, in reference to brain structure and functioning, is commonplace in contemporary culture. As Thomas Insel [35 par.6] writes, however:

the word “circuit” is probably misleading. We do not know where most circuits begin and end. And unlike an electrical circuit, brain connections are heavily reciprocal and recursive, so that a direction of information flow can be inferred but sometimes not proven.

Insel highlights the limits of metaphor when describing the brain, whereby relegating brain structure and function to notions of circuitry is misleading given our current limited understanding of this organ. The imagery of rational/organized systems of connections, such as those found in an electronic chip or electric circuit, are of limited application. The implicit danger in using such a metaphor, then, is in the temptation to experience it as “natural, necessary, and true—that is, [it] will constrain not just what we are permitted to say, but what we are also able to think and to feel from the start”.[36 p8] In the language used in the *Defeat Denial* campaign mental illness is characterized as a disruption in brain circuitry—the brain and its “flawed” circuitry are depicted as the site of mental illness. This presentation inevitably affects how mental illness itself is envisioned—as a disruption in the way connections are made in the brain. Characterizing mental illness in terms of disruption in brain circuitry, then, is likely to constrain how we are able to think and by extension take action with regards to mental illness as it defines an erringly narrow paradigm through which to understand how the brain functions and, more importantly, how it may be perceived and dealt with.

It is not uncommon for health agencies to revert to the use of shock in awareness campaigns to draw attention to a particular issue and promote the uptake of new behaviours. [23] Based on our analysis, the ways in which mental illness information was conveyed to the public in the *Defeat Denial*

campaign as both an awareness campaign and branding exercise led to an array of embedded assumptions about the origins of mental illness and its association with stigma. Not only does this paper re-affirm biomedical hegemony in the way messages about mental illness are conveyed to the public, it also highlights the difficult association between the organization’s agenda (playing up the biological roots of mental illness) and the issue of stigma which is proven to be accentuated by such biological claims. We must remain critical of such awareness campaigns as they not only constrain how we can think about mental illness but also run the risk of increasing stigma despite our best intentions to reduce it.

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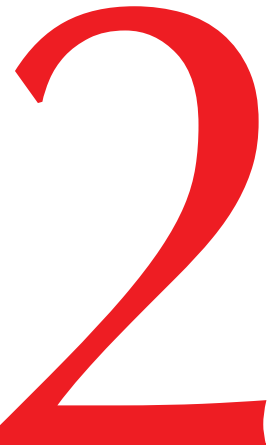
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Abstract

Devant les avancées biomédicales ainsi que l'accroissement des coûts en santé, les individus sont incités à redouter et prévenir les maladies en modifiant leurs comportements. De plus, la santé élevée au rang des vertus ou « la santéisation » s'inscrit au cœur des valeurs modernes néolibérales que sont l'autonomie, la responsabilisation et la performance. Dorénavant, la santé et les comportements de santé constituent des moyens privilégiés d'aspérer au bonheur, au bien-être et à l'accomplissement de soi d'autant plus que l'individu jouit d'un statut socioéconomique élevé. Néanmoins, la santéisation peut aussi contribuer à la stigmatisation et l'exclusion sociale en plus de renforcer le sentiment chez certains d'avoir échoué à être des citoyens responsables. Ce texte présente une analyse critique et dimensionnelle du concept de santéisation qui s'appuie, sur un cadre théorique composé entre autres, de travaux de Foucault sur le gouvernement des vivants et de Taylor sur l'individu moderne.

Key Words médicalisation, moralisation, promotion de la santé, santé, santéisation

Analyse critique et dimensionnelle du concept de santéisation

HÉLÈNE POLIQUIN

Introduction

Ce présent texte porte sur une analyse critique et dimensionnelle du concept de santéisation (en anglais « *healthism* ») s'appuyant sur un courant de pensée critique de la médecine moderne et de la promotion de la santé qui a émergé au cours des années 1970-1980. Ce travail visait à dégager les dimensions du concept de santéisation, notamment son influence dans le domaine de la santé, dans la vie des individus ainsi que dans la société en général. De plus, ce travail visait aussi à mieux comprendre l'ordre social dans lequel s'inscrit la santéisation ainsi que les forces politiques, socioculturelles, économiques et morales agissantes.

Il sera démontré que la responsabilisation individuelle face à sa santé est intériorisée par plusieurs personnes puisqu'elle constitue un nouveau cadre normatif et moral dans les pays occidentaux et démocratiques modernes. Il sera démontré que la santéisation peut être intégrée dans une éthique personnelle consciente bien qu'elle peut aussi donner cours à un désengagement social et à des glissements moralisateurs envers certaines personnes les discriminant et ajoutant à leur souffrance. Le fait que ce concept de santéisation soit très peu abordé dans les écrits scientifiques, toutes disciplines confondues, appuie l'importance de stimuler une réflexion critique sur l'ampleur que peut prendre la santé, la promotion de la santé et la maladie au plan du devoir et de la moralité individuels.

Cadre théorique

Entre autres, la thèse de Foucault sur le gouvernement des vivants[1] tout comme les travaux du philosophe Taylor[2] sur l'individu moderne ont servi de cadre théorique pour expliquer comment les individus en viennent à adhérer de

leur plein gré à des normes sociales alors qu'ils n'en sont pas contraints par la force.

En effet, au début des années 1980 Foucault a effectué des travaux de reconstitution historique du gouvernement des vivants[3] et sur les relations de pouvoir[1] dans le but principal de comprendre comment les êtres humains en viennent à se conformer moralement, de leur plein gré, aux cadres normatifs. Essentiellement ce revirement tient de sa réflexion que le biopouvoir et la biopolitique ne sont pas nécessairement en cause lorsqu'il s'agit de comprendre par quels processus les êtres humains se conforment à des pratiques de santé alors qu'ils n'en sont pas contraints par une force extérieure telle que l'État.[3]

Ainsi, Foucault expose ce qu'il nomme le « régime du savoir » à partir de l'histoire de la constitution de la moralité chrétienne par opposition à la Gnose, le champ adverse du christianisme. Deux régimes du savoir prédominent alors dans ce paradigme religieux, soit l'un fondé sur les actes de foi ou le dogmatisme et l'autre sur les actes d'aveux ou de confession qu'il nomme le « pouvoir pastoral ». [1] Foucault relie ainsi l'individualisme qui a émergé au 16^e siècle au pouvoir pastoral des autorités religieuses chrétiennes qui scrutent autant l'intérieur que l'extérieur de chaque individu afin d'assurer à la fois son adhésion à la doctrine et sa rédemption. Selon Foucault, dans les sociétés modernes, plusieurs formes de pouvoir coexistent selon une logique de pouvoir pastoral, dont la médecine où l'individu est scruté et amené à se confesser lors de consultations. Cette forme de régulation, qui se trouve au sein de tous les liens sociaux selon Foucault, amène l'individu à adopter ou à s'assujettir aux rôles sociaux attendus de lui.[1]

Taylor, quant à lui, situe l'individualisme dans les sociétés modernes au sein d'un désenchantement du monde et d'une perte d'horizons cosmiques permettant à la personne de se situer dans l'ensemble du monde. La sécularisation des sociétés a provoqué un effondrement des ordres sociaux anciens et a ainsi transformé les règles sociales dans les pays démocratiques occidentalisés.[33] Ainsi pour lui, nous assistons à la primauté de la raison instrumentale sur les grands idéaux, ce qui fait que les individus se préoccupent davantage de questions liées à leur bien-être personnel. Foucault également en arrive aux mêmes conclusions sur la sécularisation : c'est ainsi qu'une série de préoccupations liées à la santé telle l'alimentation, le bien-être ou la sexualité ont remplacé les visées religieuses qui reposaient sur des préoccupations de l'au-delà et de l'inconnu dans le but d'atteindre la vie éternelle alors qu'aujourd'hui nous cherchons à atteindre le bien-être dans ce bas-monde.[1]

Par contre, alors que d'autres qualifient ces nouveaux codes des conduites des individus de vides et de narcissiques, Taylor, y voit principalement une nouvelle forme de moralité. Pour lui, la moralité est au fondement de tout contrat social du vivre ensemble et elle peut être invoquée même dans des gestes qui pourraient être qualifiés de purement individualistes et même égoïstes, car ces gestes peuvent s'inscrire dans une compréhension qu'a l'individu de son devoir de citoyen de se conformer aux normes sociales.[2]

Méthodologie

L'analyse critique et dimensionnelle du concept de santéisation a été réalisée en s'inspirant de la méthode d'analyse dimensionnelle de concept de Schatzman[4] qui encourage l'utilisation de sources variées telles que des textes scientifiques, théoriques ou philosophiques, de la littérature grise, incluant des écrits populaires. La recension itérative des écrits a été réalisée à l'aide de diverses bases de données en sciences sociales et sciences de la santé telles que CINAHL, EMBASE, ERIC, MEDLINE, Psychinfo, thèse et dissertation, Atrium, ainsi que le moteur de recherche Google avec les mots clés « santéisation », « santéisme », « healthism », « imperative of health », ainsi qu'un autre terme anglais moins utilisé « healthization ». De plus, quelques écrits décrivant le phénomène à l'étude sans toutefois nommer explicitement la « santéisation » ont été retenus.

Au début de l'analyse thématique, j'ai cherché à dégager le plus de dimensions possibles du concept, sans essayer d'interpréter leurs significations, ni orienter les analyses.[12] Ensuite, une analyse plus raffinée a permis d'identifier et regrouper les dimensions. C'est à ce moment que le cadre théorique a été choisi et qu'il a servi à l'analyse critique qui ne visait pas à découvrir « l'essence » en terme de « vérité » ni plus d'identifier la meilleure définition que l'on pourrait donner du concept. Plutôt, il s'agissait de nommer les différentes dimensions données du concept par les auteurs qui en font usage et de retracer dans quel ordre social la santéisation a été pensée au départ et en quoi les différentes dimensions sont reliées.

Ce travail repose sur 59 textes variés d'auteurs pour la plupart critiques, c'est-à-dire, qui remettent en question l'ordre établi lorsqu'ils abordent les questions entourant la santé. Les auteurs proviennent de disciplines variées dont les principales sont la sociologie, l'anthropologie, la philosophie, les sciences infirmières, la santé publique, les sciences politiques et la criminologie.

Résultats

Les résultats sont regroupés en 11 dimensions macrosociales ainsi que microsociales de la santéisation :

La santé comme une valeur centrale

Plusieurs auteurs associent la santéisation à une valeur centrale accordée à la santé dans les sociétés modernes et y voient un syncrétisme entre les valeurs chrétiennes et les valeurs de la modernité où l'être humain glorifie la santé comme autrefois il glorifiait Dieu.[5-8] De plus, la santéisation est attribuée en partie à la sécularisation dans les pays occidentaux qui a laissé une place béante dorénavant occupée par à des préoccupations de bien-être personnel, notamment de santé.[6,9]

Crawford, auteur à l'origine du concept, relie également la santéisation qui imprègne les programmes en santé, aux valeurs individualistes centrales propres aux temps modernes que sont l'autonomie, la responsabilité et les capacités individuelles.[10] Ces valeurs phares orientent aussi les comportements et les habitudes de vie des individus vers une accentuation de la responsabilisation individuelle face à leur santé.[5-7,11-13]

C'est également devant la dépolitisation des problèmes de santé et la focalisation sur les individus, que Zola avance que : « Le domaine de la santé constitue l'exemple par excellence de la crise d'identité contemporaine de la recherche d'une définition de soi et de son devenir ». [14, p. 49] Selon Aïach, qui a réalisé des travaux importants sur la santéisation, celle-ci signifie une élévation de la santé au rang des valeurs centrales des sociétés modernes [15] En effet, ne constituant plus seulement un pilier indispensable à la vie, la santé serait devenue pour le Aïach [15] un but en soi. Dans ce paradigme de santéisation, la santé définirait les fondements de la vie, à un point tel qu'elle serait devenue tristement, déplore-t-on le seul moyen envisagé pour améliorer la condition humaine. [7,14]

La médicalisation de la vie

Pour plusieurs auteurs, la santéisation s'inscrit dans un phénomène plus grand qui est celui de la médicalisation de la vie et n'en serait en fait qu'une nouvelle forme.[5,11,14-17] La médicalisation, terme introduit par Illich,[17] signifie la traduction en termes médicaux ou la pathologisation d'un nombre croissant de phénomènes liés aux êtres humains.[11] La médicalisation est aussi associée aux progrès économiques qui ont favorisé, dans les sociétés occidentales, un meilleur accès aux soins de santé pour toute la population ainsi

qu'une demande accrue pour les soins de santé alors que les avancées scientifiques ont contribué à prolonger la vie.[6,15] Ainsi, de la même façon que la médicalisation, les discours de prévention et de promotion de la santé auraient envahi toutes les sphères de la vie. Aïach, qui a effectué des travaux majeurs sur la santéisation, s'en inquiète:

Le développement d'une idéologie de la santé et d'une idéologie de la prévention donnant force et légitimité à ce mouvement général se traduisant par une inquiétante métamorphose de questions se posant dans le domaine social et dans la sphère individuelle en questions de santé ou de bien-être/santé.[15 p70]

De son côté, Aïach distingue quatre voies principales menant à la fois à la médicalisation et à la santéisation. Ces quatre voies sont 1) la croissance des effectifs de professionnels et des institutions de santé ainsi que de leur utilisation; 2) l'extension du champ de compétence de la médecine; 3) la production d'un processus de pathologisation croissante; et enfin la santéisation de la vie.[19] Cependant, Renaud apporte une nuance additionnelle. Pour lui, la médicalisation relèverait davantage des causes et des interventions biomédicales tandis que la santéisation proposerait des prescriptions sur les habitudes de vie et sur les comportements.[20]

La promotion de la santé ciblant la modification des comportements

En 1975, le rapport canadien de Marc Lalonde[21] voulant que la santé pour tous s'obtienne essentiellement par la modification des habitudes de vie marque un jalon important vers l'accélération de la responsabilisation personnelle face à sa propre santé.[6,11] En effet, ce rapport servira de munition pour les États afin d'amener les individus à modifier leurs comportements pour prévenir les maladies, tout en se désinvestissant d'actions sur les déterminants sociaux de la santé et des causes structurelles productrices de mal-être et de maladies.[5,11,12,22,23] La maladie devient ainsi le résultat de choix des individus [11], comme s'ils étaient tout-à-fait indépendants et aptes à résister à leur environnement et à faire les bons choix pour leur santé.[5,7]

De la première définition large de la santé proposée par l'OMS de 1946 voulant que la santé soit « un état complet de bien-être physique, mental et social, et non une absence de maladie ou d'infirmité », [24 p100] a été modifiée pour passer d'une vision curative à une vision préventive axée sur la promotion de la santé et l'adoption d'habitudes de vie « saines ». En effet, selon la Charte d'Ottawa de 1986, la santé est devenue une « ressource de la vie quotidienne qui permet, d'une part, de réaliser ses ambitions et satisfaire ses

besoins et d'autre part, d'évoluer avec le milieu ou s'adapter à celui-ci ». [25] La santé est ainsi passée d'un « état » à une « ressource ».

Selon les discours néolibéraux de santéisation des dernières décennies, les habitudes de vie sont considérées comme les premiers déterminants de la santé. [14, 26] Ces discours sont perméables à toute la société et ses institutions dont notamment les écoles où plusieurs auteurs [27-29] dénoncent que les discours dominants arguant les étudiants à se responsabiliser en adoptant une saine alimentation et en faisant de l'exercice, ne tiennent pas compte des subjectivités des individus. Bien que les étudiants n'adhèrent pas tous à des comportements dits de santé, ils deviennent souvent la cible de railleries lorsqu'ils sont en surpoids ou ne sont pas conformes aux standards de beauté et de santé. [27] LeBesco inscrit ses mesures ainsi que les discours sur l'obésité dans un cadre normatif qu'elle qualifie de « panique morale » liée à la montée de l'obésité qui ciblent des individus souvent des classes socioéconomiques inférieures. [29] De plus, des auteurs soulignent que la lutte contre l'obésité omniprésente dans les discours devient discriminatoire comme si les personnes en surpoids étaient nécessairement malades. [28-30]

La prévention des risques et les discours de peur

Gori qualifie de mutation anthropologique cette nouvelle médecine qui s'éloigne de la prise en charge d'une personne malade « au bénéfice d'un gouvernement sanitaire des populations et de leurs facteurs de risque ». [16, p. 124] En effet, l'identification des facteurs de risque est au centre de l'élargissement de la définition de la santé qui inclut la prévention des maladies promue par la nouvelle médecine. [5, 7] L'identification de ces risques rend légitime l'emphase sur la prévention puisque qu'on croit que la maladie peut dorénavant être évitée [7-9]. Par contre, selon Gori, cette nouvelle forme de contrat avec une personne malade, qui est passée de passive et confiante en la médecine, à « un acteur de sa santé plus conforme à l'éthique néolibérale de notre civilisation contemporaine », s'avère tout à fait questionnable. [16 p 125]

En effet, Fugelli trouve qu'on ne se préoccupe pas assez des effets adverses occasionnés par les stratégies politiques et de santé publique. [31] Ainsi, plusieurs campagnes recourent à la peur pour mobiliser les citoyens à se maintenir en santé et à prévenir les maladies. La notion de risque est devenue centrale pour désigner une vision catastrophique de la santé et la peur de la maladie contribue à nourrir ce que Fugelli nomme l'« hypocondrie collective ». [13,16]

Notamment, puisque les individus ne peuvent contrôler leur environnement et agir de sorte à se maintenir en santé, la santéisation est également associée au stress, à la peur et à l'anxiété face à la maladie ou à l'éventualité de celle-ci. [5,11,28]

La responsabilisation et l'autonomisation des individus

Illich en 1975 fut l'un des premiers à dénoncer les mythes et limites de la médecine à guérir tous les maux dont sont affligés les êtres humains. [17] Illich, devant les limites des moyens curatifs, prétendait que les individus allaient devenir de plus en plus convaincus qu'il valait mieux se prémunir de la maladie, par des principes d'autonomie, de gestion de soi pour gérer les risques pour sa santé que de tenter de se guérir. [11,20] En partie en raison des connaissances liées aux risques à la santé et au désillusionnement face à la capacité de la médecine de tout régler, les individus sont amenés par des techniques de gouverner de soi et d'autosurveillance à prendre davantage part aux décisions relatives à leur santé et à se responsabiliser. [32]

La responsabilisation des personnes face à leur santé et leurs maladies est ainsi une dimension centrale de la santéisation. [5-7,11-13] Des auteurs attribuent le fait que les individus doivent « gérer » leur santé à l'individualisation de l'humain et sa rupture avec un filet social protecteur. [26] Cette responsabilisation s'effectue, entre autre, selon Fraser par l'autonomisation (empowerment) des individus qu'il décrit comme étant « un processus d'internalisation de problèmes externes plaçant l'individu dans une position où il se doit de prendre toutes les mesures nécessaires pour demeurer entièrement fonctionnel en société, tant sur le plan physique, psychologique, qu'économique ». [12]

Sans nier l'importance centrale de l'autonomie et de l'autodétermination dans la vie des individus, les approches visant le « self-management », les patients-experts et l'empowerment peuvent néanmoins s'inscrire dans une idéologie de santéisation qui place l'individu devant l'obligation morale de développer des capacités personnelles pour se maintenir en santé. [12, 26] Et des études démontrent que cette responsabilisation est fortement intégrée chez les individus et qu'ils s'en trouvent valorisés par cette responsabilisation sans se sentir pour autant contraints car il s'agit pour eux d'un choix personnel. [33,34] Cependant, incitée à agir en concordance avec cette norme sociale partagée, la personne devant l'injonction de devoir se prendre en main se retrouve face à elle-même, ce qui ne se fait pas sans dérives. Notamment des personnes mentionnent le

stress occasionné ne serait-ce que pour l'alimentation saine, devoir choisir parmi la pléthore de messages, de discours et d'interdiction, allant des gras, au glucides aux additifs, aux pesticides, etc., pour manger « sainement ».[33]

La santé comme un devoir citoyen et le biopouvoir

Les États et les compagnies d'assurances ont été les premiers à énoncer le devoir des citoyens à se maintenir en santé. À propos des droits et libertés liés à la santé, Crawford, cite Knowles, le président de la fondation Rockefeller qui dit en 1977 :

Ceci est justifié par les droits et libertés individuelles - mais les droits d'un homme en santé sont le fardeau d'un autre homme en taxes et primes d'assurances. Je crois que le droit à la santé doit être remplacé par l'idée d'une obligation morale de préserver sa santé - un devoir public, en quelques sortes.[11 p50]

Pierret le souligne : « Le droit à la santé et aux soins ont été remplacés par le devoir de santé et il ne s'agit plus de lutter contre la maladie mais de se maintenir en santé ». [7, p. 46] C'est ainsi, que l'individu doit conformément aux valeurs néolibérales s'ajuster à l'ordre normatif dont le principe central est l'autonomie, celle-ci devenant un support pour le démantèlement d'un système de soins universel.[7, 26] Le bon citoyen, et ceci se trouve au cœur des politiques de santé publique occidentales, doit et plus que jamais gérer sa santé en faisant le nécessaire pour protéger sa propre santé, mais également celle de ses concitoyens.[7, 14] Ainsi la santéisation fait allusion pour plusieurs à des injonctions d'auto-surveillance, et d'autorégulation de sa santé faites aux individus.[27]

D'ailleurs Lupton,[9] voit dans les nouvelles mesures de promotion de la santé mises de l'avant par les autorités de santé publique un exercice de biopouvoir ainsi qu'une nouvelle idéologie qu'elle a nommé « l'impératif de santé » qui consiste en une injonction faite aux individus de se maintenir en santé.[9] Au fondement de la santéisation, pour des auteurs qui défendent plutôt une thèse du biopouvoir et de la biopolitique, il y donc un citoyen manipulé par les autorités ainsi que par un système capitaliste.[5,11] Le biopouvoir ou la biopolitique désignent la régulation et la normalisation des corps par la surveillance médicale des individus effectuée par l'État ou les institutions.[35] En effet, certaines orientations politiques de promotions de la santé axées sur la responsabilisation des individus sont qualifiées de « santéisation oppressive » par Carter et coll.[22] À titre d'exemple, LeBesco,[29] dénonce comme étant oppressif un projet de loi américain de peser les étudiant deux fois par année en plus de publier les résultats selon leur indice de

masse corporelle dans le but de les inciter à modifier leurs habitudes alimentaires.

L'individu biologisé et soin du corps

La réduction de l'individu à ses dimensions biologiques est largement associée au processus de santéisation. Le Besco affirme que « Le corps en santé est devenu un signe du citoyen moral et méritant- qui exerce une autodiscipline sur son corps en appui à l'État et qui partage le fardeau de gouvernance ».[29 p154] Selon le Wiersma, « Le soigner, l'entretenir, veiller lorsque l'on est parent à ce que nos enfants en fassent de même participent d'une logique de santé publique fortement intériorisée notamment par les catégories les plus aisées ».[36 p56] Ainsi, on observe que les interventions sanitaires modernes curatives comme préventives, se concentrent principalement sur des objectifs visant la gestion des corps biologiques,[9] opposant d'ailleurs la santé au plaisir. Pierret remarque que certains individus, plus que d'autres sont ciblés en fonction des critères biologiques:

Aujourd'hui, le modèle de la prévention et du dépistage vise plutôt à améliorer et à renforcer la santé individuelle en anticipant la survenue de risques chez des individus sélectionnés uniquement sur la base de quelques critères biologiques ou biologisés ou des phases de la vie comme l'âge et le sexe.[7 p54]

Telle une forme d'appauvrissement de la vie, la santéisation est associée à une réduction de la vie et des activités de la vie à ce qu'elles apportent à la santé. Ainsi, on soigne son corps, on mange, on fait de l'exercice parce que c'est « bon pour la santé » et non par plaisir. En conséquence, selon une étude de Wiersma, le paradigme dominant de santéisation dans les centres des soins pour personnes âgées fait en sorte que ces personnes soient réduites par les soignants à des d'objets corporels à soigner et maintenir en santé.[36] Ainsi, les soignants contribuent aussi à déshumaniser les personnes en la réduisant à des indicateurs biologiques de santé. À petite échelle l'emphase sur les comportements individuels peut mener à ce que Cheek qualifie de « tyrannie de la santé ».[8] Une étude de Rail et coll. auprès d'adolescents démontrent que ceux-ci définissent la santé selon l'activité physique ou le poids corporel d'une personne.[37] Il aurait ainsi intégré le discours biomédical qui imprègne les programmes d'éducation physique dans les écoles réduisant l'activité physique à des objectifs de santé. [38]

Le culte de la santé, consommation et consumérisme

Les préoccupations, voire les obsessions grandissantes liées à

la santé sont également des dimensions de la santéisation. De plus, au cours des dernières décennies, plusieurs nouveaux comportements dits de santé visant l'amélioration de la santé ou l'auto-guérison tels que s'entraîner, bien manger, se faire vacciner, suivre les prescriptions médicales, prendre des médicaments ont été largement adoptés.[8,26] Le thème de santé est devenu omniprésent sur Internet, dans les livres, les revues, les médias, les centres sportifs, les spa, les livres.[11]

La santéisation fait ainsi aussi référence aux idéaux de santé, de jeunesse et de minceur qui ciblent toute la société, mais tout particulièrement les femmes.[28,29] Selon Pierret, nous voyons naître la médecine du toujours mieux qui peut nourrir une forme de renfermement sur soi, notamment en tentant de repousser le vieillissement, modifier l'apparence du corps avec la chirurgie esthétique par exemple.[39] Doucet voit la santéisation comme un nouveau paradigme des interventions en santé et constate qu' « un certain culte de la santé serait applicable à tous les niveaux de la vie sociale ». [26 p362] En effet, allant dans le même sens, Aïach lie la santéisation à tous ce qui peut profiter à l'industrie de la beauté, de la santé ou de la jeunesse.[18] Aïach décrit la santéisation comme étant :

l'importance de la santé dans l'échelle des valeurs partagées par l'ensemble de la société et l'utilisation symbolique et marchande qui en est faite par les producteurs et distributeurs de biens et services médicaux ou ayant un rapport plus ou moins lointain avec la santé- tout ce qui peut se rapporter à la triade beauté/santé/junesse.[18 p21]

Une dimension importante de la santéisation est donc le consumérisme qui consiste à faire passer les intérêts économiques du marché avant le bien-être des individus. [8] Les entreprises dont les firmes pharmaceutiques, les commerçant et mêmes les professionnels de santé eux-mêmes amassent des profits faramineux, notamment pour offrir leurs services ou vendre des médicaments, des produits amaigrissants, des produits rajeunissement ou des produits naturels de santé.[40] En effet, pour Skrabanek, la médecine n'échappe pas à la relation commerciale : « De surcroît, à la relation médecin-patient tend à se substituer une autre, de type consumériste ». [41 p228] Ainsi, le dépistage et la prévention des maladies peuvent aussi conduire à une exploitation commerciale de l'hypocondrie généralisée de la population.[16] De plus, certains auteurs réfèrent à la santéisation comme étant une obsession pour la santé à laquelle est associée l'orthorexie.[42,43] Chrysanthou définit même la santéisation comme étant un désir pathologique d'être santé.[43]. Il faut souligner toutefois que cette dernière conceptualisation de la santéisation est des plus marginales parmi les écrits recensés.

La réalisation de soi par la santé et la performance des individus

De plus en plus, dans nos sociétés occidentales, la signification de la santé s'apparente à la signification de la vie elle-même dans un paradigme englobant allant du bien-être, à la réalisation de soi, à l'estime de soi, à la joie, au plaisir, au bonheur jusqu'à l'utopie de la santé parfaite. [11] Les sociologues Adam et Herzlich évoquent l'idée de santéisation, sans toutefois la nommer en des termes de réalisation de soi :

On énonce et évalue en termes de santé un nombre toujours croissants de phénomènes individuels ou collectifs. Le corps est devenu signe, la santé est dans tout et tout est dans la santé. Pour l'individu-et d'autant plus qu'il appartient à une catégorie sociale élevée-, la santé s'inscrit dans la thématique de l'expression libre et de la réalisation de soi.[44 p73]

Revendiquer la reconnaissance de son intériorité constitue dorénavant une liberté fondamentale et fondatrice du sujet qui sert ainsi de terrain propice à la santéisation où l'individu est engagé à travailler sur soi[26] ce qui est particulièrement bien intégré chez les classes sociales moyennes et aisées. [11,44,45] Effectivement, se maintenir en santé serait plus facile pour les personnes de statut socioéconomique élevé, celles-ci pouvant d'ailleurs y trouver un réel lieu d'accomplissement et de réalisation de soi.[7,14]

Ainsi, l'atteinte du mieux-être devient une marque de performance sociale.[46] C'est ce que nous démontre une étude de Rysst auprès de personnes âgées en Norvège qui a trouvé que l'assiduité à la gym, correspondait avant tout à un désir de performance sociale plutôt qu'à une recherche de santé.[47] Également, une étude de Rich et Evans auprès d'adolescentes anorexiques démontrent que celles-ci perçoivent l'adoption de comportements de santé comme des performances sociales et qu'elles ressentent de l'anxiété et du stress lorsqu'elles n'arrivent pas à « performer » face à leur santé.[28] D'autres personnes pourraient se sentir incapables de performer lorsqu'elles sont dans l'incapacité de payer et, pour de multiples raisons elles se retrouvent au banc de la société, notamment celles qui ont des invalidités physiques ou des problèmes de santé mentale.[26,48]

La moralisation, la culpabilisation et l'autoculpabilisation

La santéisation est fortement identifiée comme un processus pouvant mener à une oppression des individus notamment, par la moralisation des modes de vies.[22,27,29,41,49] La santéisation peut aussi contribuer à accentuer les différences entre des personnes selon leur état de santé en plus d'accentuer

et même produire des inégalités sociales. Ces dernières se voient d'ailleurs davantage stigmatisées puisqu'elles sont perçues comme des fardeaux pour les contribuables aux régimes d'assurances collectives.[11] De plus, l'apparence physique hors normes telle l'obésité est devenue une cible de discrimination sociale courante. En 2012, dans un blogue sur d'un site Internet d'une association américaine pour la diversité du poids corporel « The association for size diversity and health » Ferguson dénonce la santéisation :

La santéisation prend plusieurs formes et nous devrions nous inquiéter de toutes. Les personnes dont la corpulence est perçue comme transgressive (qu'elles soient trop petites ou trop grosses) sont les principales cibles des lunettes santéistes. Les personnes obèses qui refusent un régime sont vues comme irresponsables et un fardeau pour la facture de l'assurance maladie du voisin.[50]

Aussi, « Trop manger, versus trop peu manger, ou bien manger trop d'aliments sucrés par exemple devient culpabilisant ».[51 p56] Des études démontrent d'ailleurs que des personnes ressentent le besoin de « se confesser » de ce qu'elles ont fait ou pas fait en lien avec leur santé.[30,34] Les comportements sont devenus des marqueurs importants de la valeur sociale d'un individu. Selon une étude de Rail et coll. auprès d'adolescents, ceux-ci avaient intégré la responsabilisation face à leur santé et se jugeaient eux-mêmes ou d'autres jeunes qui ne font pas régulièrement d'exercice physique comme étant paresseux et non en santé.[37]

Crawford pointe vers une accentuation de la « culpabilisation de la victime » en citant les propos très sévères de Marumoto: « Nous choisissons nos maladies quand par négligence et ignorance nous leur permettons de se propager en nous ».[11 p116] Plusieurs habitudes de vie sont dorénavant irrationnelles et irresponsables, telle que fumer ou avoir des rapports sexuels non protégés,[52-54] et la personne devient la cible de réprobation, stigmatisation, moralisation et culpabilisation parce qu'elle a échoué à se maintenir en santé.[5,11]

La stigmatisation, la discrimination et l'exclusion sociale

La santéisation est ainsi normative et prescriptive et repose sur la conviction que la réalisation de soi passe par l'intégration à la norme sociale. [26] Par exemple, l'étude de Clarke et Griffin démontre que de plus en plus de personnes dont le corps affiche des signes de vieillissement se voient discréditées puisque vieillir avec succès signifie dorénavant vieillir sans maladie, de manière autonome, en étant engagé dans sa vie tout en préservant de bonnes capacités mentales

et physiques.[53] Ainsi, « Les discours actuels de santéisation et du succès du vieillissement incitent les adultes âgés à prendre la responsabilité de leur santé et à mesurer leur processus de vieillissement selon leur capacité de maintenir leur corps en santé ».[53 p1092] En effet, deux études sur l'âgisme démontrent que la discrimination des personnes âgées malades peut être liée davantage à la santéisation qu'à l'âgisme identifiée à tort.[54,55]

En optant pour une critique foucauldienne des discours incitant les mères à l'allaitement, Holmes et coll. soutiennent que « la promotion de l'allaitement maternel s'inscrit au cœur même du néolibéralisme et que « le gouvernement » du sein de la mère constitue une stratégie de gestion anatomo/bio-politique de l'expérience de la maternité ».[56 p206] Ces auteurs soulignent que les pratiques de promotion des mères sont dorénavant régulées de sorte que celles qui n'allaitent pas subissent une réprobation sociale car elles ne font pas tout pour assurer la santé optimale de leur nourrisson. Un autre exemple de stigmatisation sociale induite par la santéisation est donné par Gagnon et Holmes en lien avec la lipodystrophie qui permet d'identifier des individus atteints du VIH « comme des déviants des normes corporelles d'une société qui adhère à un discours de santéisation et d'esthétisme ».[57 p235]

En effet, selon Crawford,[58] l'identification des « facteurs de risque » glisse vers l'identification de personnes auxquelles on appose une faiblesse, ou bien morale ou bien psychologique. Crawford donne d'ailleurs en exemple la crise du VIH/sida du début des années 1990 où l'identification des facteurs de risque ont permis à la population générale de se distinguer des « personnes à risques » qui étaient associées à la maladie et discriminées comme déviantes ou contagieuses selon leur orientation sexuelle, leur consommation de drogue ou leur couleur de peau. Ainsi la santéisation se manifeste aussi sous la forme de différenciations sociales des personnes effectuées sur la base de leur « capital santé ».

Des auteurs parlent de la santéisation comme d'un paradigme qui occulte d'autres façons d'intervenir, de penser la personne que par la promotion de la santé et l'autoresponsabilisation de soi. Comme le souligne Le Floch « de l'hyper-responsabilisation résulte la santéisation ou médicalisation de ceux dont la subjectivité a été brutalisée par les épreuves sociales, au point qu'ils sont en voie d'exclusion de toute forme de lien social ».[59 p239] Ainsi, la santéisation agit comme une idéologie qui empêche de concevoir la personne autrement que par la santé.

Comme conséquence, la santéisation occulterait la souffrance

des personnes qui affichent une faiblesse relative aux normes d'autonomie.[7,26,48] Selon Margérard, parler de santé et de bien-être serait l'une des meilleures façons de ne plus nommer ni le bonheur ni la souffrance.[60] Ceci est partagé par Doucet qui trouve que l' « on peut donc convenir que la santéisation peut être à la base d'une certaine souffrance et que le soulagement de cette souffrance se fait par le recours aux moyens mis de l'avant par la santéisation », [26 p371] soit l'autonomisation des individus. Ainsi, le paradigme prédominant de santéisation agit comme un écran qui occulte d'autres formes plus collectives de soulagement de la souffrance puisque l'individu se doit d'être autodéterminé, responsable, autonome et autonomisé face à sa santé incluant sa santé mentale.[26]

En ce qui concerne les discours populaires sur la santé mentale au Québec de 1973 à 1994, selon Lamarre et coll., [26] ceux-ci sont fortement imprégnés de la santéisation, ce paradigme dominant où la santé ou la maladie sont perçues comme étant individuelles et dans lequel l'emphase est mise sur les aspects biomédicaux et l'autonomie des individus. Dans le champ de la santé mentale, ces auteurs déplorent le manque d'attention donnée à l'itinérance, à la judiciarisation, à la désinsertion sociale ou au du fardeau des familles laissées à elles-mêmes. En effet, avec la dépolitisation de la santé, l'exclusion guette les personnes malades, les personnes en perte d'autonomie, les personnes marginalisées ou vulnérabilisées socialement.

Considérations méthodologiques

L'analyse critique du concept de santéisation en s'inspirant de la méthode de Schatzman [4] tout en y intégrant un cadre théorique a permis de dégager plusieurs dimensions du concept tout comme une certaine trame historique des travaux d'auteurs clés permettant une réflexion féconde quoi que ce travail soit incomplet et inachevé. Aussi, plusieurs courants de pensées ou théories tentent d'expliquer comment les individus en viennent à adhérer à certaines normes sociales et cette analyse est teintée d'une perspective de ce paradigme de santéisation.

Ce travail comporte de nombreuses limites. D'abord, les écrits recensés ont porté essentiellement sur des réalités de l'Amérique du Nord, de l'Europe occidentale ainsi que de l'Australie ce qui peut laisser supposer que la santéisation n'existe pas dans des pays aux différentes réalités socioculturelles, économiques et géopolitiques. Ceci n'a pas été validé. Une autre limite est celle de n'avoir pas exposé un contre discours à la santéisation, soit le rejet personnel de cette moralisation par la santé. Ce texte pourrait laisser

croire en une hégémonie de la santéisation alors qu'il ne s'agit que d'un courant idéologique et moral auquel certains individus adhèrent plus que d'autres, mais auxquels tous sont confrontés.

Discussion

Devant ces différentes dimensions dégagées dans le cadre de ce présent travail, il est légitime de demander s'il faut combattre la santéisation? D'abord, je tiens à souligner, que la santéisation n'est pas selon moi le modus operandi des États ni plus une théorie sociale expliquant les comportements humains associés à la santé, loin de là. Il s'agit plutôt d'un paradigme de plus en plus répandu au sein duquel peuvent fleurir les valeurs néolibérales. Par ailleurs, je ne suis pas certaine que l'auto-responsabilisation des individus eu égard à leur santé puisse être évitée ou même qu'elle devrait être évitée car elle est si fortement liée à d'autres valeurs sociales fortes dont les capacités individuelles, l'accomplissement de soi, la performance sociale et le devoir de citoyen. Par contre, le cadre théorique sur lequel je me suis appuyée permet de mieux saisir en quoi la santéisation pose problème et ceci dans ses différentes dimensions.

Parmi les dimensions qui interpellent, il y a la focalisation sur un être humain biologisé qui est associée à une réduction de la vie et des activités de la vie à ce qu'elles apportent à la santé. En effet, selon la thèse de Foucault, l'objectivation du corps est perçue comme un processus par lequel l'individu est assujéti à son rôle de sujet.[35] Cette objectivation du corps se fait par un processus de différenciation, entre les normaux et les anormaux, notamment les personnes malades et les personnes en santé. La valorisation de certains entraîne la dévalorisation des autres.

Également le culte voué à la santé dans la triade qu'Aïach nomme santé/beauté/jeunesse qui n'a plus de limites pour certains individus prend des dimensions inquiétantes au point qu'ironiquement, le culte à la santé est perçu par certains auteurs comme une nouvelle forme de dysfonctionnement humain.[42, 43] La faute est incessamment renvoyée à l'individu pour expliquer les supposées maladies ou troubles qui l'assaillent.

Une dimension oppressive de la santéisation est la culpabilisation qu'elle induit sur des individus pour ce qu'ils font ou ne font pas. Pour « se confesser », les personnes parlent de transgressions alimentaires en des termes religieux notamment en disant qu'elles ont « pêché » en mangeant un « aliment interdit ».[34] Ceci encore une fois peut être expliqué par la normalisation sociale qui se fait par des

régimes du savoir et le rôle que jouent les relations humaines dans le processus d'intériorisation des cadres normatifs.

Il aussi été démontré que la santé serait devenue une valeur centrale dans nos sociétés. Mais alors que Skrabanek défend que la santéisation serait menée par le pouvoir plutôt que par une préoccupation pour le bien-être des personnes et serait pour lui exempt de principes moraux,[41] d'autres soulignent que la moralité est belle et bien au cœur des représentations individuelles du devoir de se maintenir en santé.[9,11] Ainsi, l'individu participe activement à la santéisation parce qu'il y retrouve une notion de moralité et une quête de santé et de bien-être auquel il adhère. Il n'en est pas contraint. Selon Taylor, « Tout peut être repensé en fonction de la quête du bonheur et du bien-être des individus »[2] et c'est ainsi que plusieurs auteurs voient en la santé une valeur sociale prédominante. Par contre, pour Taylor tout comme Foucault, les préoccupations pour le corps et son bien-être ne sont que de nouvelles formes d'éthique personnelle. L'éthique est ainsi au cœur de l'adhésion aux nouveaux codes des conduites morales. Crawford rejoint ainsi la pensée de Taylor lorsqu'il attribue la santéisation à une nouvelle forme de contrat social fondé sur des principes individualistes : « Ainsi, l'individualisme de la santéisation pourrait bien être en fait une forme très élaborée d'affirmation d'une appartenance sociale ».[11 p382]

Quant à la responsabilisation face à sa santé qui constitue une dimension importante de la santéisation, elle peut s'expliquer par ce que Taylor qualifie de perte d'horizon et d'atomisation des individus dans les sociétés néolibérales qui contribue davantage à l'aliénation des individus. Ainsi, les individus cherchent un sens à leur vie par la valorisation de la santé. En effet, selon le philosophe Taylor, avec la modernité, l'individu se sent désormais seul devant un grand état bureaucratique.[2] Aussi, l'individualisation des problèmes de santé et de la promotion de la santé sont liés à ce que Taylor qualifie de despotisme doux et paternalistes où l'individu atomisé est dépolitisé et aliéné de la sphère politique.[2] Sans référer à une forme de biopouvoir, il convient de dire que la santéisation est largement liée à des nouveaux guides de conduites ou des régimes du savoir, entourant la santé, et que plusieurs sont subjugués par toutes ces promesses de bien-être allant jusqu'à l'utopie de la santé parfaite.

De plus, si la santé continue d'occuper une telle importance dans les sociétés occidentales, c'est qu'elle est liée au désir de l'individu de vivre exempt de maladie, de souffrance, de douleur, d'handicap et d'être valorisé en tant que personne à part entière selon des valeurs centrales des

sociétés contemporaines qui permettent l'inclusion des individus. Ainsi, soutient Fraser, les personnes se voient contraintes de se conformer à l'autoresponsabilisation afin de pouvoir fonctionner socialement.[12] En contrepartie, la santéisation peut aussi favoriser l'exclusion des personnes. Ainsi, comme le souligne Bibeau concernant des personnes socialement exclues, cette « impossibilité de se réaliser tend à produire, chez les exclus et les marginalisés un sentiment d'incompétence, d'auto-culpabilisation et de la frustration qui entraînent des troubles divers identitaires, relationnels et comportementaux ».[48 p195] Ainsi, la santéisation par son association à la performance tend à produire des perdants. Il y aurait aussi lieu de se demander avec Llorca, de quelle façon et jusqu'à quel point les sociétés contemporaines génèrent des conditions qui font en sorte que les personnes se sentent de moins en moins à la hauteur, particulièrement lorsqu'elles sont confrontées à la maladie ou à une incapacité?[62] Petite contribution, soit, mais, je pense, que l'étude d'un paradigme tel que celui de la santéisation est une façon de mieux comprendre des conditions qui font en sorte que des personnes se sentent comme des perdantes. Faut-il le souligner, la modification des comportements ne sera jamais suffisante puisque les maladies sont liées à des nombreux déterminants dont des facteurs environnementaux notamment des polluants ou à des facteurs sociopolitiques telles des politiques publiques inadéquates pour assurées la santé et le bien-être des populations.

Par ailleurs, des études ont révélé que tout le monde n'adhère pas aux maximes de la santéisation et les personnes ne sont pas des consommatrices passives des discours de santé, mais, les réinterprètent et choisissent aussi d'adhérer à certains comportements.[63,64] Néanmoins, les résultats démontrent aussi que plusieurs motivations derrière les comportements dits de santé adoptés par les individus peuvent être vraiment tout autre que la santé et être plutôt liées notamment à des objectifs de performance sociale, d'acceptation sociale, la séduction, la valorisation de soi. Ceci va dans les mêmes sens que les conclusions d'Otero sur les règles d'individualité contemporaines, qui souligne que la recherche accrue de formes de mieux-être serait axée avant tout sur des objectifs de performance sociale.[65]

Conclusion

Parmi d'autres phénomènes centraux contribuant à la santéisation, nous retrouvons : la sécularisation des sociétés, le néolibéralisme et l'individualisme. Ainsi, la responsabilisation sociale des individus liée au devoir de se maintenir en santé est rattachée à la performance sociale,

à la productivité ainsi qu'à biologisation de l'être humain qui s'est accentuée avec les avancées de la médecine par les nouvelles technologies. Ainsi, la santéisation est reconnue comme étant une élévation de la santé au rang des vertus et de la moralité. De plus, elle s'accompagne d'un devoir individuel de se maintenir en santé par la responsabilisation des individus, même si en parallèle l'État se désengage d'agir sur les déterminants sociaux, politiques et économiques de la santé et du bien-être des individus et des collectivités humaines.

Ce n'est cependant pas un hasard, qu'au sein de sociétés occidentales valorisant l'individualisme, que la médecine occupe une place aussi centrale; au point de mener à une médicalisation de la société, dont la santéisation ne serait qu'une nouvelle forme. Dans cette quête individuelle de la santé, selon les thèses foucaaldiennes et tayloriennes, il ne faut cependant pas uniquement voir une montée de l'individualisme, désintéressée du social, mais paradoxalement y voir une quête individuelle à se conformer aux normes et moralités sociales dont celle du devoir moral individuel de se maintenir en santé.

La santé est ainsi une valeur centrale très légitime et humaniste qui est liée à l'autonomie, la responsabilité, la performance. Il ne s'agit pas de dénoncer cette éthique, mais d'y pointer les dérives possibles, comme il a été fait dans ce texte. Par ailleurs, bien que la santé puisse contribuer à la valorisation de soi et de son bien-être individuel, elle peut aussi lorsqu'elle fait défaut contribuer à discréditer certaines personnes. En érigeant la santé au rang du devoir, on place le malade au rang des perdants. La maladie devient alors, dans un contexte où l'individualisme est une valeur centrale, un échec personnel. En érigeant la santé au rang de la vertu, on stigmatise, discrimine, juge et culpabilise les personnes qui n'adoptent pas les comportements sociaux attendus.

Il est important de souligner que des distinctions doivent être clairement établies entre la création de conditions individuelles et sociales favorisant la santé, la normalisation sociale de l'autoresponsabilisation face à sa santé et le glissement vers une moralisation sociale des comportements associés à la santé ainsi que de la maladie.[22] En effet, en présence d'une logique unique d'auto-responsabilisation de la personne face à sa santé, c'est la personne, et uniquement la personne, qui doit être changée et non la société.[14] Insidieusement, le contrôle social exercé par la santéisation consiste en son pouvoir à faire croire, à tort, que l'adaptation de la personne à son environnement est suffisante.

Pour l'essentiel, il ne faut pas perdre de vue, que les

individus peuvent transformer l'environnement social et le transforment quotidiennement même lorsque celui-ci est régi par des groupes d'intérêts et des classes et institutions sociales dominantes.[11] Surtout, il faut éviter, comme nous avertis Crawford [5], de voir la personne d'une façon déterministe puisqu'elle exerce le plus souvent son libre arbitre eu égard aux comportements de santé qu'elle adopte. Ainsi, en prenant conscience de la santéisation comme une nouvelle maxime sociale qui influence les individus et qui est imbriquée dans la société dans son ensemble, des réflexions sont nécessaires afin de tendre vers un meilleur équilibre entre les actions visant à transformer les individus et les actions visant à transformer le social. De plus, il est impératif de repenser la globalité des actions pour un meilleur équilibre entre les actions de promotion de la santé et de prévention des maladies axées sur un individu biologique et des actions sur d'autres déterminants de la santé qui relèvent d'orientations politiques, notamment de solidarité envers les individus en tenant compte de leurs capacités et de leur autonomie.

Il convient de souligner enfin, que ce genre d'analyse critique est essentiel à l'amélioration des pratiques cliniques puisqu'il contribue à l'approfondissement de la compréhension des différents phénomènes humains. Sans réflexion critique entourant les dimensions sociales de la santé, la science ne fait que s'inscrire dans l'avancement des connaissances contribuant à l'hégémonie des discours dominants et ce, au détriment de remises en question de l'ordre établi. Enfin, l'approfondissement de la compréhension des différents phénomènes par l'analyse des concepts établis est une activité non seulement enrichissante, mais essentielle au développement d'une pensée réflexive.

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Commentaire/Commentary

Diagnosisgate: Conflict of Interest at the Top of the Psychiatric Apparatus

PAULA J. CAPLAN

Introduction

Allen Frances, arguably the world's most powerful psychiatrist, spearheaded a massive, million-dollar project using psychiatric diagnosis to propel sales of a potent and dangerous drug by pharmaceutical giant Johnson & Johnson (J & J). Frances began the initiative in 1995, but his involvement has been little known, despite a court document written in 2010 that revealed what its author, an ethics specialist, called serious deception and corruption in that project.[1]

Frances is longtime editor of the globally influential manual of labels, *Diagnostic and Statistical Manual of Mental*

Disorders (DSM), known as the psychiatrist's "Bible". According to the court document, Frances led the J & J enterprise that involved distortion of scientific evidence, conflicts of interest, and other illegal and unethical practices.[1] The author of the court document is Dr. David J. Rothman, a Columbia University specialist in the ethics of relationships between medicine and industry. The document is an expert witness report commissioned in connection with a Medicaid fraud court case filed by the Texas Attorney General at the time, Greg Abbott.

Some mystery surrounds the matter: It remains unclear why certain crucial portions of this document have not become more widely known, given that Abbott used it as part of his case alleging wrongdoing by Johnson & Johnson subsidiary Janssen Pharmaceuticals. Major stories with references to the report appeared in 2011, 2012, and 2014 in the *Houston Press*,[2] *Businessweek*,[3] *Bloomberg.com*,[4,5] and *The Denver Post*[6] and included names of some of the other wrongdoers but not those of Frances and his two closest colleagues, whose work was the foundation of

the subsequent conflict of interest. And although in 2011, Vera Sharav of the Alliance for Human Research Protection published an online article [7] about the Rothman Report and included the names of Frances and those two colleagues, her article was apparently picked up by only two or three bloggers and not otherwise reported. The Rothman Report is in the public domain, appearing for instance on attorney James Gottstein's Psychrights.org website.[1]

The lead-up to the agreement between Frances and Johnson & Johnson

For six years, Frances had headed the task force charged with creating the fourth edition of the manual, *DSM-IV*, from 1988 until its 1994 publication by the American Psychiatric Association (APA). The APA, a lobby group, markets the book and earned more than \$100 million from that edition.[8] Under Frances's leadership, the number of categories listed as mental disorders leapt from 297 in the previous edition (published in 1987) to 374 in his edition a mere seven years later.[9] He then headed production of the minimally altered *DSM-IV-TR* that appeared in 2000 and remained in force until *DSM-5* was published in 2013. Thus, over two decades, the editions he edited were used in the labeling as mentally ill of millions more people than anyone else in history, which is why he has been called the world's most important psychiatrist.[10]

Despite evidence that the *DSM-IV* committees ignored and distorted [9] the science behind the categories of mental illness they included in the manual, Frances has continued to the present time to describe their work as "scrupulously scientific." [11] Despite evidence that the new labels failed to help therapists reduce patients' suffering and that they carried enormous risks of harm – including plummeting self-confidence; loss of employment, child custody, security clearance, and the right to make decisions about one's medical and legal affairs; skyrocketing rates of disability, etc[12]—for many years, he continued to defend psychiatric diagnosis as simply helpful and to deny the harm it could cause. Not until 2009 did Frances begin to warn about harm from psychiatric diagnosis. This new stance coincided with his campaign against the *DSM-5* that was then in preparation and on whose task force he was not included. From 2009 to the present time, in his critiques of *DSM-5*, he has often contrasted its problems with what he described as the scientific rigor of *DSM-IV* and *DSM-IV-TR*, [11] thereby positioning himself as a staunch advocate of high standards of research methodology and accurate representation of scientific findings.

Frances's campaign against *DSM-5* continued in his book, remarkably named *Saving Normal*, and included repeated warnings that Pharma would use *DSM-5* labels to promote their drugs. As a result, many people have come to regard him as an opponent of drug companies. Adding to the impression of Frances as concerned about harm from diagnostic labels, his anti-*DSM-5* writings, speeches, and media interviews have included what appeared to be his frank admission of errors by his *DSM-IV* Task Force; that is, he acknowledges that his *DSM-IV* led to three epidemics of diagnosis – Autism, Attention Deficit Disorder, and childhood Bipolar Disorder.[11,13,14,15] Despite calling this admission a mea culpa, he in fact absolves himself of blame, saying repeatedly in articles and in his book – which appeared at the same time as *DSM-5* – that he and his colleagues could not have foreseen these epidemics. He lays the blame elsewhere – largely on Pharma, but also on other psychiatrists, non-psychiatrist physicians, therapists, patients themselves, researchers, consumer groups, the Internet, and the media. [11,14,15]

Rothman's revelations about Frances' work for Johnson & Johnson

The scrupulously documented Rothman Report contrasts starkly with the image of Frances as wedded to rigorous research and as an opponent of Pharma. Rothman reported that, in 1995, the very year after *DSM-IV* appeared, Johnson & Johnson had paid more than half a million dollars (USD) to Frances and two of his psychiatrist colleagues to create an official-seeming document as the basis for promotion of one of their drugs. The following year, the drug company paid them almost another half million dollars to continue and expand the marketing campaign.[1]

The practice guidelines

The initial document that Frances and his two fellow psychiatrists produced was the "Schizophrenia Practice Guidelines." Practice guidelines are presented as state-of-the-science instructions to practitioners about how to treat people who have received a particular diagnosis. Such guidelines are considered the "gold standard" of evidence-based care because they aim to convey what is deemed to be the most reliable scientific evidence at a given time. Those who follow them are often absolved of responsibility for harm that may result, because they are considered to constitute the standard of care. The APA itself produces most of the psychiatric practice guidelines, and its website includes the statement that "APA practice guidelines provide

evidence-based recommendations for the assessment and treatment of psychiatric disorders.” [16] Thus, practice guidelines are presented as being based on objective evaluations of the relative effectiveness of various treatments for a specific condition. It should be noted, however, that there is no external regulation of the guidelines, and thus those who create and promote them are rarely, if ever, held accountable if they misrepresent the state of the relevant scientific research. In fact, recent investigation has shown that professional panels creating guidelines have tended “to increase the number of individuals considered to have the disease[s], none reported rigorous assessment of potential harms of that widening, and most had a majority of members disclosing financial ties to pharmaceutical companies.”[17] In the same vein, a 2011 Institute of Medicine report included the note that “There are no universally accepted standards for developing systematic reviews and clinical practice guidelines, leading to variability in the handling of conflicts of interest, appraisals of evidence, and the rigor of the evaluations.”[18]

Nowhere in the *DSM* and its associated books and other products (such as casebooks, research reviews, and webinars)[19] has the APA disclosed the poor scientific foundation of the symptom clusters underlying the proposed disorders.[9,11,12] It is troubling, then, that diagnostic categories with poor scientific bases have led to the production of ‘authoritative’ practice guidelines.

According to the Rothman report, Frances and his colleagues wrote guidelines that were designed specifically to persuade physicians to prescribe J & J’s drug Risperdal as the first line of treatment for schizophrenia.

Frances was Chair of Psychiatry at Duke University at the time. In keeping with drug companies’ common practice of funding faculty at high-status institutions, the two other psychiatrists chosen to develop the guidelines with Frances were Professor and Vice Chairman of Psychiatry at Cornell University, John P. Docherty, and Associate Clinical Professor of Psychiatry at Columbia University, David A. Kahn. The three psychiatrists received \$515,000 of J & J funding in 1995 to produce the Schizophrenia guidelines, which before they were even written were referred to in J & J correspondence as the “RISPERDAL Treatment Guidelines.”[1 p16] J & J gave an initial, “unrestricted” grant of \$450,000 divided evenly among the three psychiatrists, promised an additional \$65,000 if they produced the guidelines fast, and paid that bonus when they speedily came up with what were called the “Tri-University Guidelines.”[1 p15-6]

According to the Rothman report, the Guidelines were constructed “in disregard of professional medical ethics and principles of conflict of interest,” and they “subverted scientific integrity, appearing to be a purely scientific venture when it was at its core, a marketing venture for Risperdal.” [1 p14] Internal emails provided to Rothman showed that Frances communicated frequently with J & J officials, failing “to keep the company at arm’s length” [1 p15], and that Frances and his team promised “wide distribution of its Risperdal product, including publication in a journal supplement”[1 p15] aimed at legitimizing the Tri-University guidelines even further.

Risperdal was one of a number of then-new drugs called atypical antipsychotics. They were so named to distinguish them from the earliest drugs that were marketed as antipsychotics, such as chlorpromazine (Thorazine©) and haloperidol (Haldol©). Frances, Docherty, and Kahn omitted from the guidelines the evidence that the atypicals were not more effective than these earlier drugs [20]. Atypicals were bumped up to the position of first-line treatment for Schizophrenia, and of the atypicals, Risperdal was recommended over the others.

Frances was deeply involved in planning for the use of the guidelines in marketing, keeping in close communication with J & J and requesting their input on drafts of the guidelines. In Rothman’s words, Frances wrote to a J & J official “without embarrassment or equivocation” that “[w]e also need to get more specific on the size and composition of the target audience and how to integrate the publication and conferences with other marketing efforts.”[1 p15]

Using the guidelines to increase sales of Risperdal

Once the guidelines were written, Frances, Docherty, and Kahn created a new entity they called Expert Knowledge Systems (EKS) for the purpose of using additional J & J funds to create and help implement a Risperdal marketing plan.[1 p15] EKS required a further \$428,000 to fund their multi-arena plan, which included to “influence state governments and providers” [1, p. 16], including but not limited to officials connected with prison systems and mental health departments. Another goal was to identify Key Opinion Leaders (KOL)-psychiatrists J & J paid to give speeches advertised as Continuing Medical Education lectures about psychiatric treatments that specifically promoted Risperdal.

The Crucial Role of Texas. EKS’s promotional plan importantly targeted the Texas Medication Algorithm Project (TMAP). TMAP, which started in 1995, is one of a number of programs with the stated goal of identifying people with mental illness

as early as possible in order to start treatment right away; it is based on the assertion that early drug treatment improves long term outcomes. TMAP has been criticized as screening for mental illness using instruments skewed toward the positive identification of psychiatric symptoms and, therefore, the classification of subjects as mentally ill rather than as normal. The project was funded by a Robert Wood Johnson grant and several drug companies and included the University of Texas and that state's mental health and corrections systems.[21]

"Algorithm" sounds exceedingly scientific and precise. This is problematic in light of the unscientific nature of psychiatric diagnoses and of the major flaws and conflicts of interest in much drug research. Solid information about what medication actually helps with what symptoms remains minimal, to the point that many prescribers will favor a "trial and error" approach in which they try to identify the best course of drug treatment for patients. Moreover, major drug companies have recently drastically cut back on their research and development of new psychiatric drugs because, after decades of research, so little is known about how these drugs affect the brain and how a given individual will respond.[22]

EKS stated to J & J its "intent to work with the State of Texas immediately in implementing this product in a select number of CMHCs [Community Mental Health Centers] with the assistance of A. John Rush, M.D.," a key TMAP member.[1 p16] They reasoned that what TMAP implemented, other states could then replicate with minimal investment.[1 p18] Rush had previously been involved with Frances. Frances had appointed Rush one of two people to decide whether to put Premenstrual Dysphoric Disorder (PMDD) in the *DSM-IV* after Frances' committee of experts about premenstrual matters failed to reach a clear consensus. PMDD is an alleged mental illness whose very existence had not been proven; the European Union's equivalent of the Food and Drug Administration had declared that it was not a real entity [23]. Yet Rush was instrumental in ensuring that PMDD appeared in *DSM-IV* as a Depressive Disorder. This was noteworthy, because a woman did not have to suffer from depression in order to meet the PMDD criteria [23] and because Rush conducted Pharma-funded research about depression [9].

Along with Frances, Docherty, and Kahn, Rush became one of the instructors for the continuing medical education courses based on the Tri-University Guidelines. According to the Rothman report, J & J provided funding specifically to TMAP to promote its endorsement of Risperdal, relying heavily on the Tri-University Guidelines. Rush was critical to this process.[1] A major consequence of the J & J funding in

Texas was that, according to an internal J & J report, Dr. Steve Shon, director of that state's Department of Mental Health, "can and is influencing not only the \$50m [million] atypical [atypical antipsychotic drug market] in Texas, but likewise in many other states." [1 p24]

The involvement of Rush, Shon, and other Texas psychiatrists constituted such egregious conflicts of interest that the State of Texas in 2012 filed another lawsuit against Johnson & Johnson and its subsidiary, Janssen Pharmaceuticals, this time for violating the Texas Deceptive Trade Practices Consumer Protection Act.[24] The Medicaid fraud suit, for which the Rothman Report was commissioned, had gone to trial and ended in a settlement in which J & J would pay \$158 million.[20] The new Consumer Protection filing accused the defendants of engaging in "false, misleading, or deceptive acts or practices in the course of trade and commerce." Highlighted in that filing was that the drug company "masked, withheld, or failed to disclose negative information contained in scientific studies concerning the safety and efficacy of Risperdal." [24] This included evidence that Risperdal was promoted for treating many conditions for which it had not been approved by the FDA, including Schizoaffective Disorder, Pervasive Developmental Disorders including Conduct Disorder and Oppositional Defiant Disorder, Aggression Agitation, and Dementia. The state requested that the drug company be permanently enjoined from misrepresentations of Risperdal and be required to pay up to \$20,000 per violation.

On August 30, 2012, Texas Attorney General Abbott issued a press release to announce that Texas and 36 other states had together reached a settlement in which Janssen was to pay the states a total of \$181 million because of its "unlawful and deceptive marketing." [25] Here there appears another mystery: Interestingly, nowhere in either the filing or the press release did the names of Frances, Docherty, or Kahn appear, although their deceptive guidelines were the foundation for the enterprise, nor did they include the names of the other psychiatrists whom Janssen had hired to carry out the deceptive acts. Furthermore, they did not include information about harm done to the individuals who had been prescribed Risperdal.

Risks from Risperdal fail to prevent expanded use

Both U.S. and European government data have shown Risperdal to be one of a number of atypical antipsychotics which over the years have been prescribed for less and less serious emotional problems (e.g., distractibility, anxiety, insomnia, depression), including in adolescents and

even children.[26-29] Its use is marked by a vast array of negative effects on a striking number of physical systems. These include drowsiness, dizziness, nausea, vomiting, diarrhea, constipation, heartburn, dry mouth, increased saliva production, increased appetite, weight gain, stomach pain, anxiety, agitation, restlessness, difficulty falling asleep or staying asleep, decreased sexual interest or ability, vision problems, muscle or joint pain, dry or discolored skin, difficulty urinating, muscle stiffness, confusion, fast or irregular pulse, sweating, unusual and uncontrollable movements of face or body, faintness, seizures, Parkinsonian symptoms such as slow movements or shuffling walk, rash, hives, itching, difficulty breathing or swallowing, gynecomastia in male children, and painful erection of penis lasting for hours.[28] Yet Rothman showed that J & J produced papers presented as scientific, in which they claimed that long term use in children was safe (though it had not been studied over the long term) and that fully 20% of all children need long term treatment with Risperdal for “significant psychiatric illness.”[1 p63]

Papers impelled by J & J were published in scholarly journals and, as Rothman reports, ghost-written by individuals selected by J & J, with high-profile names affixed as first authors after the articles had been written. These papers helped promote use of Risperdal to treat not only Schizophrenia but also Childhood Onset Schizophrenia, Schizo-affective Disorder, Bipolar Disorder in Children and Adults, Mania, Autism, Pervasive Developmental Disorder other than Autism, Conduct Disorder, Oppositional Defiant Disorder, Psychosis, Aggression Agitation, Dementia, below average IQ, and disruptive behavior. Subsequent to the production and marketing of the Tri-University Guidelines came the FDA approval of Risperdal to treat adults and then children diagnosed with Bipolar Disorder, and finally children diagnosed with Autism.[24] In light of Frances’s sustained claims that he could not have foreseen the epidemics of diagnosis of Childhood Bipolar Disorder, Autism, and ADHD (see “distractibility” above), it is all the more striking that major media coverage of the trial and settlement did not mention his essential role in promoting them.

Information was omitted in other instances as well. Take for instance a 2010 article about Frances in *Wired* magazine.[29] The article included two statements pertinent to the contents of the Rothman Report, although the Rothman Report was not mentioned. The *Wired* article included (1) that one of Frances’s “keenest regrets” was the epidemic of children diagnosed with Bipolar Disorder that began “shortly after” *DSM-IV* was issued, and (2) that Harvard psychiatrist Joseph

Biederman, the most prominent advocate of that diagnosis and the use of Risperdal in children given that label, had failed to disclose money J & J had paid to him. Unmentioned in the *Wired* piece was Frances’s own connection with J & J, which was likely unknown to the author of that article. Biederman’s actions were facilitated by what Frances had developed “shortly after” his *DSM-IV* was published, specifically, the very next year: The Tri-University Guidelines and related marketing plan actually legitimized Biederman’s actions.

Recent developments

Frances has continued in various public arenas to cast himself in ways that are directly contradicted by his dealings with J & J. On September 2, 2014, on “The Doctors” television show, in an episode called “The secrets your doctors may not be telling you,”[30] Frances said he was alarmed about the “tens of millions of people on psychiatric medication” because of Pharma’s influence and “salesmanship,” which is “not good practice.” Without disclosing his own role in J & J’s miseducation of physicians, he warned that “doctors need to be reprogrammed from the propaganda they’ve received from the drug companies.” He specifically named Childhood Bipolar Disorder as a massive diagnostic epidemic and warned that children given that diagnosis “get dangerous medication that makes them gain lots of weight.” As noted, weight gain is one effect of Risperdal. Without revealing the unscientific nature of the diagnostic manual he and EKS used as the takeoff point for their work, he cautioned that “getting a diagnosis can change your whole life,” and doctors “shouldn’t jump into diagnosis prematurely.” He advised the audience to “Be informed. Ask lots and lots of questions. Don’t be satisfied with obscure answers. Get clear answers”. However, he did not divulge that their doctors would be unaware of the conflicts of interest and distortion of research that led to the EKS Practice Guidelines and their use to develop the marketing campaign (continuing medical education courses, medical journal articles) described in the Rothman Report.

On October 24, 2014, in a panel discussion at the Mad In America International Film Festival near Boston, Massachusetts, again without divulging his work for J & J, Frances presented himself as alarmed about overdiagnosis and overmedication, specifically naming antipsychotic drugs, among others, and citing Pharma’s profit motive as a major contributor to harm done to patients. His remarks included the following dramatic statements:

We’re terribly overtreating kids and old people

who don't need medication.... The figures for overtreatment are startling.... The drugs that kill are much more the drugs that come from drug companies than the drugs that come from drug cartels... Until recently, the antipsychotics were amongst the biggest revenue producers for the drug companies -- \$18 billion a year. ...Horrible problem with overtreatment for many people who don't need it, largely pushed by a diagnostic system that's too loose, drug company misinformation.... So we have this terrible problem where we're doping up the population, we don't know the effect of these drugs on kids long term, we do know that the drugs -- the anti-psychotics particularly -- make kids fat, make almost everyone fat, with all the risks that come with obesity. We do know that they shorten life expectancy in nursing homes. So there's a scandalous overtreatment... of the people who don't need it, we need to control the drug companies, we need to reduce the amount of primary care medicine that's giving out pills haphazardly, we need to control the diagnostic system... diagnosis has been terrifically oversold, and I've done my best to point that out.... We all have a responsibility, we all need to meet that responsibility.[31]

When panel moderator Robert Whitaker said that diagnosis is not reliable or valid, Frances responded: "I know the flaws of the diagnostic system better than anyone, having worked on this for many years, and I've criticized in oodles of writings... they're not useless... They still serve heuristic value when they're used well. They still help to predict prognosis, they still help to guide treatment when they're used well." And in a later statement, he stated: "The drug companies... inundated [physicians] with marketing... How do you stop this? Big Pharma has to be tamed. And that's impossible, because they spend tens of billions of dollars with misinformation to everyone and control the government." Referring to "overdiagnosis, overtesting, overtreatment" he asserted that psychiatry needs to "be reformed." [31]

Frances was invited to deliver a lecture on November 14, 2014, to the International Society for Ethical Psychology and Psychiatry. The conference announcement shows the title of his talk as "Where Ethics Meets Practice in Psychiatric Diagnosis and Treatment" and includes the following:

Psychiatric diagnosis can be extremely helpful when done cautiously and correctly, but extremely harmful when done exuberantly and carelessly. "Mental disorders" are no more and no less than constructs—necessary and useful, but also fallible and subjective. Experience teaches that anything that can be misused in the *DSM* will be misused—particularly under the pressure of well-financed drug company propaganda that mental disorders are under-diagnosed, are easy to diagnose even by untrained primary care doctors, are caused by a chemical imbalance, and require a pill solution. The combination of an overly inclusive *DSM* and misleading Pharma marketing has resulted

in a massive mislabeling as mental disorders what are instead the expectable everyday aches and pains of everyday life and of childhood development. ... The sad result is that we are massively over treating people who don't need it.[32]

In his half-hour, November 14, 2014 lecture at the ISEPP conference [14], he alluded to irresponsible diagnoses of mental disorders and their lack of scientific basis numerous times:

- He called it "absolutely absurd" and "an elaborate overestimate" to state that one quarter of our population is mentally ill and said it is "bad for society to think that one-fourth of individuals are sick. The line between mental disorder and normality is fuzzy....there's no clear, bright line that separates distress, traumas, aches and pains of everyday life from mild mental disorders";
- He referred to "the foolishness of the medical model";
- He called psychiatric diagnosis "disease-mongering, spreading misinformation" that mental disorders are underdiagnosed;
- He gave as an example of medicalizing normality through diagnosis that "Childhood is now a disease," referring to classification as mental illnesses ordinary childhood behavior.[14]

Also within that half-hour, he attributed harm to the drug companies five different times, saying:

- "[We are] terrifically and terribly overtreating with medication people who don't need it...driven by [Pharma]";
- [Psychiatrically diagnosing ¼ of the population is] an elaborate overestimate. The drug companies love it;
- [Psychiatrists have conveyed the impression that emotional problems are] easily treated with a pill;
- [Specifically naming antipsychotic medication, which as seen above was the subject of the Tri-University Guidelines and EKS marketing campaign, naming as a serious problem that] 50% of antipsychotics are prescribed by primary care doctors [whom he described as unduly influenced by drug company advertising]; and
- We have more deaths from prescription pharmaceuticals than we do from street drugs, more from drug companies than from drug cartels.... We give people in nursing homes medication if they get agitated...it reduces their life expectancy...more deaths when people go on anti-psychotics... [anti-psychotics and mood stabilizers are] given out like candy to kids, childhood obesity problem is made worse, metabolic syndrome, cardiovascular risk, we should be much more careful whom we give medication to....[14]

In this last series of statements, one notes that the prescribing

of Risperdal for people in nursing homes and for children were some of the outcomes targeted by the J & J campaign [1]. There is no indication that the campaign included warnings that the serious symptoms Frances listed in this lecture ought to lead to a conservative approach to prescribing that medication.

Also during the lecture, he drew the direct line from use of *DSM* diagnoses to use of psychiatric drugs: “A straight medical model that doesn’t think about the person...treating people with checklist *DSM* things is ridiculous, not understanding the psychosocial context is absurd, interviews that [lead to] a prescription [is not good]”. [14]

Following Frances’ lecture and one by Robert Whitaker immediately afterward, both speakers participated in a question-and-answer session, during which Frances three more times warned of the harm caused by Pharma and three more times described serious problems with psychiatric diagnoses. [14] One questioner noted that Frances had overseen the largest increase in psychiatric diagnoses in history and that this had led to increased use of psychotropic drugs, especially in children. Frances responded by claiming that his work on *DSM-IV* and *DSM-IV-TR* had been responsible and scientific. He stated that they had received suggestions for 94 new diagnoses but included only two. [14] It should be noted that *DSM-IV* actually included 374 categories, 77 more than the 297 in *DSM-III-R*, which was published seven years earlier. Moreover, the increase between Frances’s editions and *DSM-5* actually took place at a slower rate. [9, 12] Frances claimed that for his editions:

We set up a very conservative standard...before [a diagnosis was] added,[we did] extensive literature reviews, field trials. Our standard was that we wouldn’t add anything new unless it could be proven but we wouldn’t subtract unless it could be proven.

In another statement, he presented himself as an open, critical thinker: “You need to be as critical of your own views and the ways they may be biased.” [14] One example he gave to illustrate how he avoided pathologizing normal experience was that in *DSM-5*, “grief became Major Depressive Disorder.” Curiously, in his *DSM-IV*, under Major Depressive Episode (MDE, my emphasis), the common manifestations of grief were described as criteria for diagnosing MDE even on the first day of bereavement. [12] In the same response in which he stressed the scientific foundation for his editions of the *DSM*, he also said that, in *DSM-IV*, psychiatric categories were considered to be “constructs”. [14] He urged that there be blackbox warnings about the problems with psychiatric diagnosis [14] (something that had been suggested by this

author in a previously published article [12]). Also in that response, he acknowledged that “The APA has done a lot of wrong things” [14], something he had long denied about his manuals [9,12] but said that to blame the guild interests of psychiatry for harm to patients “tremendously underestimates the power of the pharmaceutical industry.”

Whitaker referred to Frances’ denial that psychiatrists had created a disease model through the *DSM*, noting that a disease model was indeed used in *DSM-IV*. “We were told these were diseases”. Frances replied that “the real problem in the world is that Pharma companies control Washington, the airwaves... the APA is a Wizard of Oz thing,^a remarkably stupid. Big Pharma has power and dollars, and they control the narrative.” He said further that he had “fought this conception as hard as I can, the overdiagnosis...” [14]

In a subsequent article in *Madinamerica*, [15] Frances described himself as “no defender of the APA” and said he has “harshly condemned its incompetence and financial conflict of interest”. He declared that the APA “became far too dependent on drug company money” but did not mention his own employment by Johnson & Johnson. His attacks on Pharma’s misleading marketing were extensive, including the following from the online article:

The real gorilla in the room is Big Pharma. The drug companies are rich, are powerful, are clever, and are highly motivated to spend billions of dollars selling pills to push pills. Big Pharma’s massive marketing campaign has convinced the public and doctors that life’s everyday distresses and problems are really undiagnosed mental disorders caused by a chemical imbalance requiring a pill solution... The effective marketing muscle is all with Big Pharma... The only meaningful way to contain the quick-draw craze for medication is to end all direct-to-consumer Big Pharma advertising (allowed only in the US and New Zealand) and all marketing to doctors. This strategy of ending marketing propaganda worked to contain previously impregnable Big Tobacco — it could also work also to stop Big Pharma and to protect people from pills they don’t need. [15]

Such statements give the impression that Frances is a white knight aiming to warn and protect the public from Pharma. How could fellow professionals and the public, reading such statements, ever suspect that he had created the Johnson & Johnson marketing campaign for Risperdal?

It is important to note, however, that in the same article, [15] Frances wrote:

...medication is used way too often for people who don’t need it, but my clinical experience, research experience, and reading of the literature convince me that it has an essential role in stabilizing people

during what are often risky acute psychotic episodes and also in reducing the risk of relapse.... it is risky and clinically unsound to argue against medication for people *in the midst of an acute episode of psychosis*. ... there are people who desperately do need medication and do terribly without it.... So I heartily support Bob's [Whitaker's] crusade against over-medication when it is inappropriate, but worry that it can be harmful when extended to those who really do need medication to stabilize symptoms that will otherwise get them into prison or on the street. [15, my emphasis]

It is noteworthy that the one kind of drug whose use remains important for Frances is antipsychotic medication, the kind for which he created the Johnson & Johnson campaign.

The December 2014 issue of *Lancet Psychiatry* carries a piece by Frances[33] that includes many strong assertions supporting use of psychiatric drugs. He makes no mention still of his previous dealings with Johnson & Johnson. He states that the *DSM* has "lent itself to pharmaceutical company disease-mongering"; that "Big Pharma has also had a large role in the promotion and profiting from biological reductionism, with the misleading marketing ploy that symptoms result from a chemical imbalance that requires a chemical solution"; and that, along with housing and social support, for example, drugs are "essential ingredients for a flexible and responsive treatment system". He then warns that one must not deny the need for drugs, "even for those who most obviously need it [sic]".[33] He asserts in addition that "Mental health disorders are clearly associated with very complex and perhaps undecipherable genetics," a claim often used to promote the notion that individuals who suffer emotionally must have physiological/chemical imbalances that justify the use of psychotropic drugs. He also claims that *DSM-III* improved reliability and consistency of diagnosis. Though incorrect [34], this claim about reliability and consistency is relevant because of the use of the medical model embodied by *DSM* to justify the prescription of psychiatric medications. Remarkably, despite the *Lancet's* policy regarding the mandatory disclosure of conflicts of interests, Frances writes after his one-line biography, "I declare no competing interests." [33] Conflicts of interest of the kind documented in the Rothman Report therefore remain obscured.

As recently as January 12, 2015 in a blog post called "The crisis of confidence in medical research," Frances warns of the dangers of drug companies' misrepresentation of scientific findings and of their high-powered marketing and concealment of harm:

It's been many years since I have trusted anything I read in a medical or psychiatric journal. ...findings never seem to replicate; benefits are hyped; harms are hidden. Drug companies bear most of the blame -- the research they sponsor is shoddy and market driven. Scientists are also to blame when they torture data so much it will confess to anything. Medical journals are to blame when they publish positive findings from lousy studies and reject negative results from well done studies.... The only responsible courses of action are to improve designs and measures, standardize implementation, change sponsors, achieve complete transparency, report harms as thoroughly as benefits, and eliminate hype.... But it is clearly allowing the fox to guard the henhouse to give drug companies the franchise in conducting the studies that lead to the regulatory approval of their products. The huge financial rewards will inevitably lead to badly biased implementation that cannot be adequately corrected even if there is complete after the fact transparency. [35]

A start on prevention of harm

Psychiatric diagnosis is completely unregulated.[9,36-38] No one other than the APA controls what goes into the *DSM*, and no one has held them accountable for their claims that it is scientific, helpful, and not harmful. This allows for the opacity of enterprises involving the use of diagnoses in ways that are both unscientific and unethical and that often lead to harming the very people who have turned to the mental health system for help. Essential solutions include:

- Legislative bodies' hearings about psychiatric diagnosis, to provide a respected forum where those harmed by diagnosis can testify about it, and legislators can begin to explore ways to establish regulation of creation and use of these labels.
- Creation of entities to oversee and regulate the creation and application of psychiatric labels, including blackbox warnings on all publications and other products involving psychiatric diagnoses;[36-38]
- Establishment of entities charged with systematically soliciting, collecting, and publishing information about harm from diagnosis; and
- Establishment of entities given the mandate of ensuring that restitution is made for financial and other kinds of losses impelled by psychiatric labels. [12,37,38]

Attempts were made, via the filing of complaints by those harmed by psychiatric diagnosis, to persuade the American Psychiatric Association's Ethics Committee and the United States Department of Health and Human Services' Civil Rights section to do any of the above. The complaints were summarily dismissed with no attention to their merits.[36-38]

Current biographical information

Rothman is a specialist in medical ethics and the Bernard Schoenberg Professor of Social Medicine at Columbia College of Physicians and Surgeons, the medical school of Columbia University. He is also director of the Center for the Study of Science and Medicine at Columbia and at the time of writing his expert witness report was president of the Institute on Medicine as a Profession.[39]

Currently, Frances is Professor Emeritus at Duke University [40]. Docherty is Adjunct Professor of Psychiatry on staff at Cornell Weill Medical College.[41] Kahn is the Diane Goldman Kemper Family Clinical Professor of Psychiatry Emeritus, Columbia University Medical Center; and attending psychiatrist, New York Presbyterian Hospital.[42]

Timeline

1988: Allen Frances is appointed head of American Psychiatric Association's Task Force to prepare *DSM-IV*.

1994: *DSM-IV* is published.

1995: TMAP is created.

1995: Allen Frances on behalf of himself and his colleagues John P. Docherty and David A. Kahn informs Janssen Pharmaceuticals that in return for \$450,000, they will create Practice Guidelines to treat Schizophrenia, specifying that atypical antipsychotic drugs are superior to earlier antipsychotics and that of the atypicals, Risperdal is the drug of choice. Janssen pays them this sum and an extra \$65,000 for producing those Guidelines quickly. Risperdal has not been approved by the FDA to treat Schizophrenia.

1996: Allen Frances informs Janssen that he, Docherty, and Kahn have constituted themselves as Expert Knowledge Systems and for an additional \$428,000 from Janssen creates "multi-arena plan" to market the Guidelines.

1996-present: Multi-arena plan includes articles ghostwritten by Janssen that expand use of Risperdal, including for distractibility or Attention Deficit Hyperactivity Disorder (ADHD), Autism, and Bipolar Disorder in children, as well as a host of other indications, such as agitation, disruptive behavior, insomnia, and below average IQ. Many people suffer from negative effects of Risperdal.

2000: *DSM-IV-TR* is published with minor changes from *DSM-IV*.

2009: Frances begins to critique editors of in-preparation *DSM-5*, warning that it is unscientific and will cause harm, especially by facilitating heavy marketing of psychiatric

drugs by Pharma. His critique frequently includes explicit contrasting of the *DSM-5* work with his work on *DSM-IV*, which he repeatedly describes as scrupulously scientific.

2009-present: Frances continues his critique of *DSM-5* and representation of *DSM-IV* as scientific. He frequently acknowledges three "epidemics of diagnosis" caused by *DSM-IV* – Attention Deficit Hyperactivity Disorder (ADHD), Autism, and Bipolar Disorder in Children, but he denies responsibility for these and attributes much of the blame to Pharma.

2010: Ethics expert David Rothman writes expert witness report, concluding on the basis of internal documents from Janssen that there have been serious conflicts of interest.

2011-2014: The names of Frances, Docherty, and Kahn are not mentioned in five articles in major media about the Rothman Report – Houston Press, December 14 2011; Businessweek, January 18 2012; Bloomberg.com, April 12 and June 11 2012; and Denver Post, April 14 2014 – although one major blogger, Vera Sharav, named the three on June 15 2011 in her essay about the report.

September 2, 2014: On "The Doctors" television show, Frances makes statements warning the public about the harm that he and EKS specifically impelled, but he does not mention his involvement with J & J that led, and continues to lead, to that harm.

October 24, 2014: At the Mad In America Film Festival in Massachusetts, Frances again neglects to reveal the work he did with J & J, while he expresses alarm about misuse of psychiatric diagnosis and about the "startling" overmedicating of children and the elderly. He specifically names antipsychotic drugs and blames both drug companies for providing misinformation and misuse of psychiatric diagnosis.

November 14, 2014: Frances gives an invited address titled "Where Ethics Meets Practice in Psychiatric Diagnosis and Treatment" in Culver City, CA, at International Society for Ethical Psychology and Psychiatry conference. The abstract in the conference announcement includes that "Psychiatric diagnosis can be...extremely harmful when done exuberantly and carelessly," that "'Mental disorders' are no more and no less than constructs...fallible and subjective," and that diagnosis can be misused under "pressure of well-financed drug company propaganda that mental disorders...require a pill solution". His presentation is filled with warnings about the fallibility and harm caused by psychiatric diagnosis, the way the diagnoses lead to prescription of psychiatric drugs,

and Pharma's hard-selling of their drugs through misleading the public.

December 2014: In a *Madinamerica.com* article, Frances cites Pharma for its intense and misleading marketing but strongly asserts the usefulness of antipsychotic drugs in particular. The same month, in a *Lancet Psychiatry* article, Frances makes strong statements supporting the use of psychiatric drugs even while attacking Pharma for using psychiatric diagnosis for purposes of "disease mongering". He declares that he has no competing interests.

Notes

^aIn Caplan P J. Response to the *DSM* wizard. *Canadian Psychology*, 32(2), 1991, 174-175, I had compared Allen Frances and his colleagues to the Wizard of Oz, because when the lack of scientific foundation of the *DSM* and the harm often caused by psychiatric diagnoses were pointed out, their defense was to claim that critics did not know what they were seeing.

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