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Whose account matters? A challenge to feminist psychologists

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Abstract

Most critiques and commentaries concerning the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders (DSM) focus on the expanding scope of the system, on particular categories of disorder, or on unwarranted claims about the biological bases of symptoms embedded in DSM descriptions. In contrast, this essay focuses on phenomenology, the subjective experiences of those supposedly being categorized by this whole framework. In addition to allowing us to see extreme states and unusual perceptions, thoughts, actions, and feelings with fresh eyes – from the perspective of the distressed person's own categories and explanations – a phenomenological approach forces us to confront important ethical and political issues often ignored in discussions of diagnosis and treatment. Feminist psychologists in particular need to think more deeply about these issues, to avoid taking untenable moral positions and violating core assumptions about the right to define one's own experience.

Keywords

psychosis, phenomenology, DSM, first-person accounts of mental illness, hearing voices network

Most critiques and commentaries concerning the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders (DSM) focus on the expanding scope of the system, on particular categories of disorder, or on unwarranted claims about the biological bases of symptoms embedded in DSM descriptions. I want instead to turn our focus to phenomenology, to the subjective experiences of those who are supposedly being categorized by this whole framework.

Taking a phenomenological viewpoint means starting from the lived experience of those who are distressed or diagnosed and trying to understand what particular

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thoughts, feelings, actions, or states of mind mean to *them*. Phenomenologists explicitly work to identify their own presuppositions about the experience under investigation, to set these aside to whatever extent this is possible, and thereby see the phenomenon with fresh eyes, from the perspective of the other person's categories and explanations. This is extremely difficult to do, and in principle is never fully achievable since we cannot think without presuppositions, but the effort to 'bracket' our own assumptions, as this process is often described, is crucially useful. It pushes us to try to understand psychological experience in ways we might never have come to on our own. And in so doing, we are often forced to confront complicated ethical and political issues that might otherwise remain ignored.

I will argue in this essay that the biggest problem with DSM-5 is not that it includes, or does not include, any particular category of disorder, or that it explains symptoms in one way rather than another; the problem is that this new edition continues unchallenged the tradition of adding to a profusion of diagnoses that are already so far away from lived experience as to have little clinical use. Although some jaded practitioners may regard the DSM as little more than a list of code numbers to use in getting reimbursed for their services, most people – the general public as well as many mental health professionals – see the manual as describing 'real' categories of psychiatric illness. I think that feminists and other critics of the DSM would be better off learning what people actually find helpful in understanding and coping with their problems, rather than participating in the ultimately sterile exercise of arguing about categories that turn out to have little relation to anyone's actual experience.

I have come to this conclusion after reading, watching and listening to hundreds of the first-person narratives of madness that date from the 15th century to the present, and now appear at an increasingly rapid rate. These accounts provide an extraordinarily rich source of data, offering unparalleled insights into mental life, despite remaining largely invisible to historians or to psychologists. Since 1997, I have compiled a formal bibliography of these works; the 5th edition (Hornstein, 2011) lists more than 1000 titles. (And these are only the ones published as books and available in English. No one knows how many other madness narratives remain in personal collections or were published in other languages.) There is now also a growing number of oral history collections, blogs, and videotaped interviews available as sources of testimony by people diagnosed with psychiatric illnesses (Hornstein, 2009).

I am not a clinical psychologist, and do not offer services to individuals. My data set, as a result, is much broader than that of my colleagues who are psychotherapists, including, most notably, the accounts of people who struggle with emotional distress without the help (or in spite of the harm) of mental health professionals. Taken together, people's own depictions and analyses of suspicion, self-harm, voice hearing, despair, mania, and many other extreme states often turn out, quite strikingly, to be at odds with anything the DSM has had to say about mental illness.

As a phenomenologist, my starting assumption is that in order to be meaningful, diagnostic categories must derive from lived experience. It's not categorization itself that is problematic; I can certainly imagine wanting to have criteria that

distinguish one type of suffering from another, especially if effective treatment depended on doing so. Indeed, since phenomenology is a systematic method for arriving at a description of the structure of an experience (i.e. the characteristics that make it different from all other types of experience), the creation of distinguishing categories is often a goal. But this kind of categorization is nothing like the DSM; in phenomenology, the categories emerge directly from the data of experience, they are not a preconceived classification system imposed on the data, regardless of how well or how poorly it fits. In searching for a system with sufficiently high reliability among users that it could be sold across the world, the American Psychiatric Association has sacrificed validity to such an extent that the DSM now bears little relation to the phenomena it seeks to describe and categorize.¹

For example, consider hearing voices, which the DSM calls ‘auditory hallucinations.’ People who have this experience often find the *content* of their voices – i.e. what the voices are actually saying – to be crucial to understanding and coping with them. But the DSM focuses solely on whether the voices are audible to others, and denies entirely the existence of positive, non-pathological voices, despite increasing empirical evidence documenting their prevalence and importance (Corstens et al., 2008; Romme and Escher, 1989; Romme et al., 2009).

Besides doing violence to people’s own experience of themselves, the categories, language, and assumptions of the DSM have now been imposed on so many aspects of our lives (or the lives of our families) in the USA that the manual is now routinely referred to as ‘the Bible of psychiatry’ (presumably because it is both authoritative and awe-inspiring). The massive publicity and marketing of DSM categories – both by the American Psychiatric Association and by the drug companies – has created a ‘colonizing discourse’ that robs people of the right to understand their minds in other terms. Categories that do not remotely fit the data of experience are being used to frame our psychological lives, with little regard to the consequences.

My language here comes from an article by the activist writers Dillon and May (2003), both of whom have been on the sharp end of psychiatric diagnosis and treatment and are now part of efforts to create a fundamentally different way of understanding serious emotional problems. They argue in a much-cited paper (‘Reclaiming Experience’), that the imposition of clinical categories on the lived experience of those with mental health problems constitutes a ‘colonizing discourse’ that prevents people from being able to understand their own psychologies. Dillon and May, both of whom are British and thus well versed in the resonant language of colonization, are making the ethnographic argument that indigenous ways of making sense of experience are being supplanted by the categories and concepts of colonizing professionals, who take it for granted that their ways of understanding mental life are superior to those of the natives (Watters, 2010).

At issue here are core questions about what constitutes the appropriate data upon which to base our understandings of mental life. Psychiatrists increasingly affirm their reliance on ‘evidence-based medicine,’ yet remain distressingly dismissive of the evidence of first-hand testimony. Even clinical psychologists, often more

willing to assign weight to the case history in assessing a patient, still focus largely on pathology, reframing key aspects of the person's life as 'symptoms' or as evidence of 'personality disorder.' Clinical case conferences reinforce a view of people with 'severe and enduring mental illness,' in the current phrasing, who are assumed to have no capacity to cope with their distress and no framework within which to make sense of what is happening to them. But immersing myself in hundreds of first-person narratives by patients like these over many years has made me question many of the core assumptions about psychosis that are taken for granted by most mental health professionals.

My question is this: What happens if we listen at a far deeper level to what people actually say about their experiences (even of severe distress) instead of seeing their mental lives primarily as a vehicle for advancing our own categories and theories? What if we took people's own accounts *not* as gibberish, or as some kind of code for us to decipher, but instead as meaningful and accurate (even if fragmentary and contradictory) ways of making sense of their own minds and life histories?

There's no question that people will use the diagnostic categories and symptom criteria of the DSM to make sense of their feelings, thoughts, and actions if they have no alternative; *some* explanation is always preferable to none at all. It's too terrifying to think that events – mental or otherwise – are random, that they have no pattern of significance. (That's how the marketing slogan 'depression may be caused by a chemical imbalance,' which has no basis in science, nevertheless came to be adopted by depressed people themselves.) But once meaningful alternatives to the whole DSM way of thinking are offered, people vote with their feet against the straitjacket of those categories. The Hearing Voices Network, for example, an international federation of researchers and activists led by people previously diagnosed as schizophrenic, has pioneered the development of an alternative framework for understanding and coping with hallucinations and delusions that is attracting interest across five continents (see www.hearing-voices.org; www.intervoiceonline.org; www.hearingvoicesusa.org).

Such efforts notwithstanding, the DSM remains extraordinarily influential, and in the USA has become ubiquitous as a framework for making sense of thoughts, actions, and feelings that are distressing or depart too sharply from those of one's social group. People need *some* way of understanding the functioning of their minds and bodies, and latch onto whatever viewpoint they hear about most. If you feel physically ill and are exposed only to Western medicine, you automatically think, 'I might have X problem in my Y organ.' It's only if you are also exposed to Chinese medicine that you might instead think, 'maybe the chi is blocked in my gall bladder meridian.' With physical problems, we typically don't have our own personal accounts of what is happening, and are happy to defer to the expertise of whichever professionals we put our faith in. But when it comes to psychological problems, people often *do* have their own frameworks of meaning which differ from those of their doctors, and if these were taken more seriously both by professionals and by a person's friends and family, it might be far easier to make sense of his/her anomalous behavior or feelings.

I wrote *Agnes's Jacket: A Psychologist's Search for the Meanings of Madness* (Hornstein, 2009) to highlight the significance of first-person madness narratives and to show how radically our thinking about emotional distress changes once we start from assumptions that emerge from testimonies like these. Now, four years after the book's publication, I realize even more clearly how profoundly these data of direct experience have reshaped my ways of thinking about madness and treatment. Analyzing hundreds of published narratives and videotaped oral histories; participating for more than eight years in peer-led support groups, conferences, and strategy sessions; and meeting with activist patients from all over the world have changed core parts of my thinking. And what I've learned from people's direct reports of their experiences contradicts practically everything I assumed about mental illness from my PhD studies and three decades as a professor of psychology. For the first time in history, there is now a systematic alternative to understanding madness and treatment based entirely on first-hand experience, and it offers a powerful challenge to our taken-for-granted ideas.

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As a teenager fascinated by psychology, I roamed around public libraries discovering the works of Freud and other theorists. I loved these books, which introduced me to the unconscious, a world that became central to my thinking about myself and other people. But at some point I realized that there was also a way to understand madness from the inside, through the books written by people who'd been mad themselves. 'They seemed more gripping than other writing,' I said in *Agnes's Jacket*, 'equal parts adventure story, Gothic tale, travelogue, and morality lesson. Even the titles fascinated me: *Behind the Door of Delusion* (by 'Inmate Ward 8'); *Brainstorm*; *A Mind Mislaid*; *Holiday of Darkness*; *Chastise Me with Scorpions*.' The more books like these I read, the more bewildered I became. When I later began to study psychology seriously, I was astonished to find that these first-person narratives simply were not mentioned by professionals, even at the iconoclastic graduate school (Clark University) where I did my PhD. Why didn't psychologists find these accounts of 'a mind that found itself' – in Clifford W Beers's memorable phrase – as intriguing as I did, as windows into the very phenomena to which our field was devoting such interest?

When, after some years of collecting these works, I realized that there were hundreds of published first-person madness narratives, I started compiling them into a bibliography so that the perspectives of patients could become better known. The first edition of this bibliography, which began circulating in the late 1990s, had 300 titles. But as more and more people sent me references (or the books themselves), and as the madness narrative genre started to proliferate rapidly once most long-stay, locked facilities closed and patients had more and more opportunities to write and publish their ideas, dozens of new titles emerged (Hornstein, 2002). Over the past 10 years, I have had to revise this bibliography four times to keep up with the number of new titles; the most recent edition, completed at the end of 2011, now includes more than 1000 first-person accounts. (Again, these are only works

that have been published and are in English.) Collecting these first-person accounts, and analyzing and teaching so many of them over the years, has profoundly affected how I think about psychology. What had once simply been a secret hobby to discover and read these unusual books has become the empirical basis for a radical change in my understanding of how the mind works.

Really listening to people who've been seriously distressed is hard on many levels, but surely one of them is realizing that the assumptions and theories of professionals might simply be wrong. First-person narratives of madness contradict many of the key claims about psychosis held by psychiatrists and psychologists, and these differences cannot just be ignored. For me, as a phenomenologist, the key first step is acknowledging the inherent subjectivity of each standpoint, including ours as professionals. A helpful language has emerged in the UK to describe these different perspectives: 'expertise by experience' and 'expertise by training.' By creating a greater sense of parity between these two sources of knowledge, we can all better appreciate what can be learned from people whose experiences differ from our own. Phenomenology is especially helpful here, because it focuses on articulating the links between a person's way of knowing and the standpoint she starts from (e.g. lived experience vs. technical knowledge). When we are trying to understand phenomena as complex and variable as psychotic states, every type of contribution should be welcomed. Now that more and more people with shared experience of anomalous states (e.g. voice hearing, feelings of suspicion, self-harm, etc.) are coming together to better understand their experiences, important insights are emerging, from which we can all learn.

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The approach of the Hearing Voices Network (HVN) offers the most powerful example of a model for understanding and coping with a serious form of distress – hallucinations and other psychotic states and feelings – that has emerged directly from the data of first-person experience. Over the past 25 years, voice hearers from all over the world – often in collaboration with sympathetic 'experts by training' – have created a strikingly effective alternative to the medical model of hallucination. This alternative, which uses the content of the voices to understand and modify the person's response to the experience, and relies on peer support groups as the main intervention, is now attracting increasing attention from both voice hearers and clinicians. By focusing on the function that the voices serve – rather than on trying to stop them from occurring – HVN's approach is starting to reshape standard assumptions about hallucinations. Although not explicitly framed as 'feminist,' this approach has had special appeal to the thousands of women who have finally had the reality of their own experiences – especially of sexual violence – taken seriously and used as a source of insight into what might actually help them.

Hearing voices is an extraordinarily intense experience. You're walking down the street, or you're in your own bedroom, or you're a child in the playground of your school, and all of a sudden someone you cannot see starts speaking to you (or commanding you to do something, or several voices begin speaking *about* you).

At first, you may think it's some kind of illusion, but if it happens repeatedly, you simply have to have *some* framework to make sense of the experience; it's just too bizarre not to have an explanation. Initially, it might not make much difference whether you call what is happening a 'spiritual emergency' or 'schizophrenia' or 'the capacity to intuit presences from another realm'; what is most crucial is having *some* kind of account. But of course the consequences of adopting one of these views rather than another are quite different, especially since some view-holders have the authority to impose their particular type of intervention on the person regardless of whether or not he or she wants it.

By constantly revising its criteria for what constitutes 'schizophrenia,' the DSM gives the impression of being based on the latest science, further strengthening its claims to authority. But people who hear voices often see these diagnostic criteria as having little bearing either on understanding, or on coping with, what's happening to them. They find explanations like 'spiritual emergency' or 'extreme sensitivity' to be more accurate and likely to lead to an intervention that could be pragmatically useful to them. Of course psychiatrists can force patients to give lip service to the medical model ('yes, doctor, I have a mental illness and am taking my medication'), but they cannot keep people from privately struggling to understand their minds in their own terms. Because HVN has made clear from the outset that it welcomes all explanations – its goal is self-determination, not the imposition of any one viewpoint – people have flocked to the peer support groups it has pioneered to figure out their own ways of explaining what is happening to them.

If you have an anomalous experience – strange, intense feelings, or weird mental states, or perceptions that do not match up with other people's – it's very hard to figure out what is happening on your own. Even in ordinary circumstances, we turn to other people to make sense of puzzling situations: 'Do you hear a noise?', 'Does this milk taste off to you?', 'Are you as angry about this as I am?' If something truly extreme or unusual happens, we need other people to help us figure out the meaning of what's occurring. This does, however, leave us vulnerable to whatever view is presented most forcefully, especially in the early stages of a bewildering experience.

People who come to hearing voices peer support groups always come in with *some* kind of framework for their experiences, based either on what doctors have told them or on their own ideas. But because HVN explicitly welcomes people with many different types of explanation (including the medical model), it's likely that whatever view a person comes in with will develop or change as they are exposed to other ways of thinking. (In my experience, there isn't actually much difference between how people in hearing voices peer support groups respond to learning that there are multiple frameworks for understanding voice hearing and the ways my students at Mount Holyoke College respond to learning alternative ways of thinking about psychology. Both groups are intrigued and want to figure out what these differences mean.) Psychiatrists try to discourage people who hear voices from thinking about the experience or telling anyone about it, but this often makes the person feel even more isolated, confused, and strange. HVN groups do precisely the opposite; they enable people to feel safe enough to talk openly about their distressing experiences (often for the first time), which makes them feel

more like other people and less anomalous. This is extraordinarily important for anyone, but especially for women, to finally be able to discover what they themselves think about their own thoughts and feelings, and to reassert basic ownership over their own mental lives.

These goals sound straightforwardly appealing, especially for feminists. Who among us wouldn't support a woman's right to define her own experience? But there hasn't actually been quite the same enthusiasm by feminist psychologists for a woman's right to her own mental life as there has been about her right to her physicality. 'Our bodies, ourselves' hasn't seemed to extend fully to psychology. We haven't been as willing to embrace a diversity of viewpoints about mental life, especially those that contradict our own values or assumptions.

One of the hardest lessons I have had to learn from my study of first-person madness narratives is that my attitude about an explanatory framework or a treatment method might not be shared by those with direct experience of it. For example, some people find the long-term use of psychiatric medications or ECT (electroshock treatment) to be life-saving; others insist that their anomalous experiences are best explained in spiritual terms. Neither of these is a viewpoint I share personally, but as a phenomenologist, I can't claim that some frameworks of meaning are 'authentic' or 'valid' and others are not; every account is real to the person who conceives it and whose experiences it makes sense of. Respecting the diversity of madness experiences often requires making room for perspectives that are disconcerting to our own sensibilities.

Jane Ussher's recent book, *The Madness of Women: Myth and Experience* (Ussher, 2011) vividly illustrates these complexities. Claiming at the outset to offer a 'multifactorial analysis' and a 'rigorous exploration of the myths and realities of women's madness,' the book then proceeds to privilege only certain kinds of explanation. 'Narratives of resistance,' for example, and accounts that provide support for a view of 'therapy as tyranny' get ample attention, whereas women who find diagnoses or medications or ECT to be useful are made to seem as if their viewpoints lack authenticity.

This is a dangerous position, both ethically and phenomenologically. Are feminist psychologists any more entitled to make judgments about how women should or shouldn't think or feel about themselves than traditional psychiatrists are? Is it really progress to substitute one group's criteria for 'mental health' for another's? We rail at the hegemony of the DSM, but aren't we risking some of the same problems if we impose our own judgments on women who don't share our assumptions?

'Bad faith' is what Sartre called a certain kind of inauthenticity, in which you implicitly assume a set of values that cannot be questioned, without acknowledging that this is what you are doing. For feminists to judge women who agree to ECT or hospitalization as somehow less capable of choice (duped by their doctors, too desperate to reason properly, etc.) is deeply distressing, suggesting that we somehow know what constitutes effective treatment for everyone. Do we really want to be taking the same moral position as the psychiatrists many of us have criticized for so long?

Years of immersing myself in first-person madness narratives has made me acutely sensitive to the extraordinary variability in people's experiences and the crucial significance of a match between the metaphors used by doctor and patient to describe successful treatment. If you think, for example, like Carol North, author of *Welcome, Silence: My Triumph over Schizophrenia* (North, 1987), that the terrifying voices and visions that plague you are caused by some kind of toxin, then you will embrace the suggestion, made by your physician, that a form of kidney dialysis might cure your schizophrenia. (As indeed North was dramatically cured once she was treated in this fashion.) But if, in contrast, you think like Marie Cardinal, author of *The Words to Say It* (Cardinal, 1983), that hallucinations are symbolic manifestations of family trauma, then psychoanalytic treatment of the kind Cardinal undertook will work (as it in fact did—even for her somatic symptoms). People's psychologies are incredibly complicated and contradictory, and it's crucial to understand how they themselves think about what's going on in their minds and what might work to help them. That's why I've come to a radically subjective understanding of madness, one that resists categorization except as metaphor, and reaffirms the right of every person to make choices about what happens inside her own mind so long as this does no violence to anyone else.

Besides emphasizing the right of each person to express his or her own views about treatment – a right that every adult treated for a physical ailment is automatically accorded – this radically subjective view of psychosis can help to illuminate the phenomenon from many different perspectives. This points to the biggest problem with the DSM; it stands in the way of our actually understanding the very difficulties it is supposedly classifying. Psychology may have abandoned behaviorism in the 1980s after the 'cognitive revolution' restored the mind as an object of study, but the DSM is still based entirely on external description, as if a person's own experience of the classification of her 'symptoms' is of no relevance to understanding them. Indeed, it's probably this key aspect of contemporary practice in psychiatry that has led so many hundreds of patients to write their own books, to record their own oral histories, or to flock to peer support groups where they can articulate and share their own views of what is happening and what interventions or strategies might actually prove useful. As feminists, we should embrace these acts of self-determination, even if we disagree with the content of some people's ideas about how their minds work.

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It is by no means easy to change our thinking in the ways I am suggesting. A phenomenological perspective is complicated and difficult to put into practice, and requires close interrogation. In an extremely useful recent paper, the philosopher and mental health worker Morgan (2008) considers in detail what it would actually mean to accord greater authority to 'lived experience' in our understandings of other people's psychologies. He challenges the prevailing positivism that remains implicitly attached even to the views of those with emancipatory politics, who talk

as if ‘lived experiences [are] something one [can] grasp and relate to in a straightforward manner.’ Quite rightly, Morgan makes clear that ‘one cannot claim narratives of self-experience as some kind of fact or evidential ground without an interpretation and examination of the forces that constitute and allow them into speakability.’ In other words, contrary to the popular slogan, data do not ‘speak’ to us in unmitigated fashion. We cannot simply ‘listen to patients’ to reformulate our ideas about emotional distress, especially with complex experiences like psychosis. Indeed, the sole generalization that can be made about the history of psychiatry is that every single approach that has ever been developed – from the most bizarre to the most sensible-sounding – has succeeded with some patients and not with others. Multiplicity and contradiction are what emerge most clearly in this story, and we need to take this diversity far more seriously.

I challenge feminist psychologists in particular to embrace the ethical standpoint that motivates first-person accounts of madness to be created in such profusion. The fact that hundreds of people with lived experience of psychosis have felt the need to publish their own narratives should give us pause. Why do they feel such a strong need to express their own viewpoints? What are they trying to tell us? Why aren’t we paying more attention to what they are saying?

There are important practical consequences to starting from first-person experience in thinking about emotional distress of all kinds. There are consequences for how we research psychological problems and for how we intervene to help those who are suffering. But we can’t fully understand the implications of taking this kind of phenomenological approach until we have a fuller sense of the diversity of perspectives. Learning more about the work of the Hearing Voices Network, for example, can be a helpful first step in beginning to challenge standard views of psychosis. If you teach in a clinical setting or in a mental health training program, you can work to include first-person accounts of madness (and the many resources available from HVN at www.hearing-voices.org) in your standard curriculum. My *Bibliography of First-Person Narratives of Madness in English* can be freely downloaded and distributed from www.gailhornstein.com. A well-stocked ‘recovery library’ of accounts by people who have recovered fully from schizophrenia and other psychoses can be made available to patients at clinics, hospitals, and professional offices. Recovered patients often single out such accounts as having been crucial to restoring their mental health. And there is no substitute for taking the time to read first-person madness accounts yourself and recommending them to students, colleagues, patients and families, to begin to break the hegemony of the DSM narrative.

We are now living at perhaps the most fascinating moment in psychiatry’s history – the moment when patients’ accounts of psychosis are in a position to rival those of professionals. In no other clinical field could such a challenge even be possible, and it offers a profound challenge to our taken-for-granted ways of thinking. Rather than spending time figuring out how to pathologize more and more aspects of human psychology, as those drafting DSM-5 seem intent on doing, why not ask ourselves what we can learn from those who experience states of mind we ourselves aren’t privy to?

Note

1. In this respect, its authors have departed widely from the practice of Emil Kraepelin, the prominent 19th-century psychiatrist whose classification system inspired the original DSM. Kraepelin has been rightly criticized for holding to a biological model of degeneration with a shaky empirical base, but his actual categories are directly based on his careful observations of the natural history of symptoms in thousands of patients. They are thus far more phenomenologically grounded than contemporary DSM categories are (Carlson, 1981; Kraepelin, 1902).

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