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Nev Jones
Mona Shattell, PhD, RN, FAAN

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COMMENTS, CRITIQUE, AND INSPIRATION COLUMN

Not What the Textbooks Describe: Challenging Clinical Conventions About Psychosis

Nev Jones, PhD
Felton Institute, Department of Research and Evaluation, San Francisco, California, USA

Mona Shattell, RN, PhD, FAAN
Rush University, College of Nursing, Chicago, Illinois, USA

Edited by
Mona Shattell, RN, PhD, FAAN
Rush University, College of Nursing, Chicago, Illinois, USA

Edited by
Michelle Cleary, PhD, RN
University of Tasmania, Faculty of Health, Sydney, Australia

The co-authors of this commentary have recently published multiple peer-reviewed publications grounded in a series of studies designed and pursued while working as advisor and advisee at DePaul University in Chicago. These include pieces on the subjective nuances of perceived agency in the onset and development of psychosis (Jones et al., 2016; cf. Sass & Parnas, 2003); oscillations between states of doubt and certainty as to the nature of perceptual and experiential changes (Jones, Kelly, & Shattell, 2016; cf. Sass, 2014); the messy overlap between the putatively distinct domains of “hallucinations” and “delusions” (Jones & Luhrmann, 2015; cf. Humpston & Broome, 2015); the richly entitative qualities of voices (Jones & Luhrmann, 2015; cf. Woods, Jones, Alderson-Day, Callard, & Fernyhough, 2015); and the frequently erotic and/or sexual aspects of altered sensory experiences (Jones, Luhrmann, & Shattell, in preparation).

For our initial study (first launched in 2013), we conducted phenomenological interviews with approximately 20 community members, some living in the community and some in group homes or residential settings, who reported experiencing psychosis or unusual experiences. These participants were demographically diverse, representing a broad spectrum of ages, socioeconomic and cultural backgrounds, and life experiences. Our analyses and the aforementioned associated papers strongly challenge conventional oversimplifications of the experience of psychosis in the areas of psychopathology and phenomenology as well as treatment and healing.

One of us (NJ) has extended personal experience of schizophrenia-spectrum psychosis and associated outpatient and inpatient treatment. As a distressed and disempowered young woman—roughly a decade ago—she had concluded that the mis-fit between her experiences and those laid out in leading psychiatric textbooks (e.g., Sadock, Kaplan, & Sadock, 2007) underscored the idiosyncratic and un-shared nature of the changes she was experiencing. It was not that the textbooks were wrong, that is, her experiences were. Over the years, extended work in direct peer support roles as well as clinical research and advocacy, have strongly countermanded this early assumption; very few people’s experiences of “psychosis” or “schizophrenia” in fact map onto conventional understandings of either psychopathology or healing. The psychoses, for lack of a better term—that is, the experience of voices, visions, special messages, and alternative realities—are both profoundly heterogeneous and conjoined in their complex intersections with identity, culture, and fundamental processes of thought and perception. For many people with enduring psychosis, at least some, if not all of the time, “psychotic” experiences cannot be separated from the self: to experience psychosis, that is, is to experience a radically changed self. Before reflecting on our work, we briefly reiterate the major themes of our conversations with participants in the following sections.

OUR FINDINGS

Almost universally, research participants across our studies struggled to explain and communicate their experiences. The things they had seen and felt, they told us, simply did not map onto available terms and constructs. As one participant explained:

I would reiterate the extreme difficulties [involved in] trying to explain and describe these experiences. When I talk to other people...
becomes incredibly tempting to resort to easier terms and terms that clinicians understand because [the inability to communicate] gets so frustrating... I often want to—in this kind of negative way—to [instead] resist interpretation, and [instead] say “that’s not right” or “that didn’t capture it” without necessarily having a positive alternative; no “this is what it’s like.”

Interviewers were prepared for such responses, reassuring participants of the enormous difficulties involved, and collaboratively digging deeper. Where did existing language fail? What were available terms failing to capture? For many participants, once these difficulties were acknowledged, the most solid change they could communicate was a series of fundamental, “invisible” or nonliteral, changes in their experience of and interaction with the social and physical world. Whether gradually or suddenly, many came to a point where they knew with certainty that their perception of things (or perhaps there sense of being or existing) had profoundly changed, even though they could not say why. The fabric of the world—the fold and feel of things—had subtly but resolutely altered. For many, boundaries between thought and perception also began to blur in uncanny ways; had a voice or touch been “felt” in the figurative or the literal sense? Had they really felt it, or had “imagination writ large” brought it to life? For others, it no longer seemed clear that many commonplace assumptions about the nature and structure of the world were in fact as solid as they had once seemed. “One’s entire experience,” explained one young woman, “in other words, [one’s experience] of the world and of how one is situated in it and of one’s self changes. It’s like one aspect of [these changes] can maybe get pulled out and described as a “voice,” but [such terms] are just explanations. They’re just explanations or a way of articulating to other people this kind of fundamental breakdown in everything.”

Asked to think back to the earliest onset of symptoms, many participants reported significant confusion as to the degree of their own agency in pursuing and even embracing nascent changes. One young woman, for example, described the initial draw of perceptual alterations and anomalies—anomalies, she reported, that were not that far afield from the psychedelic states her freshman friends and colleagues sought through LSD or hashish. Others found themselves entranced by much more intense spiritual or religious preoccupations and proceeded to explore these. In other cases, our interviewees noted a variety of real or possible motivations: wanting or needing to escape from things, feeling unable to cope with everyday disappointments or the heartbreak of a bad breakup. Still other descriptions of early agency took on the flavor of a confession:

Wanting it to be one thing or the other... clearly madness [and outside my control] or clearly not madness... It’s hard to tell what was going on psychologically, but I kind of felt like, was I, like did I, kind of just in order for a sense of closure and certainty, try to push myself over the edge...?

Attempts to communicate such nuanced but critical concerns to clinicians, several reported, invariably backfired: “none of this is your fault,” well-intentioned therapists reassured them, and the conversation ended there. Participants, however, rather than feeling reassured, often felt even more isolated, even more misunderstood. One woman, convinced that she, unlike others, had actively sought out her initial psychotic break, insisted that we not categorize her as a person with “true” psychosis. Theirs’—the psychosis of others—she confided, had been a “surprise,” something passively foisted on them; hers had been sought out.

Participants also repeatedly challenged any clear-cut distinction between periods of psychosis and periods of remission (or insight). For many, unpredictable fluctuations between everyday reality and unusual experiences and beliefs were instead the norm, even during periods in which their clinicians considered them asymptomatic. In-between more overt episodes, shadowy figures, in both the literal and figurative sense, lingered; at times, it was, as one participant put it, liking living in “two different realities simultaneously.” These experiences, participant narratives underscored again and again, virtually always rehearsed or replayed themes and variations grounded in personal histories as well as social and community life. Individual trauma was often a core part of this, but also vicarious adversity and socioenvironmental contingencies, as well as participants’ spiritual practices or faith traditions. Some reported “speaking” with ancestors or the spirits of dead loved ones; others a “flowing” of deeply personal life energies inside them. One deaf participant, described by his sign language interpreter as a “poet with his hands,” stunned us with the unconventional power and beauty of the images he wove:

When I lie down to sleep and I’m quiet, then I can stop (the voices) or ignore (them). And the ghosts, it’s sort of like I shoved them away. And there are so many ghosts there... so many of them. And also, you know, there’s like a character that’s like a queen standing there. It’s not a father figure, but it’s like there’s my mother, who I love so much. There are so many—almost like all of the seeds... all of the seeds that are growing inside of her stomach. There’s a smell, like they’re... like it’s growing. Like the sperm is there, and you can smell it. And there’s blood that you can smell. And it’s just... it’s just amazing. There’s this inside feeling of like... there’s a rope—like the baby’s umbilical cord is around a neck and then there’s a waking up. There’s a Hallelujah to the Lord. And there’s a connection there to God. And this is sort of an awful full of blood experience. And there’s so much love for my mother. This is the same as the voices; it’s the same.

Sometimes the motifs participants described were political, but never in a socially disconnected way: actual personal (or community) risks and threats undergirded virtually every “conspiracy”-themed narrative we heard, involved, or piggybacked on actual experiences of (or exposure to) government surveillance, terrorist plots, and police or gang violence. One participant, for example, gestured toward the street and explained that just a few weeks prior, four blocks away, over a dozen community members had been gunned down in gang crossfire at a public park. His voices, he said, warned him not to go out on days they perceived him to be at risk, or, in some cases, instructed him to take safer routes or avoid public transportation. Others described histories of repeated exposure to threats or violence in the context of military service or on the streets.
Some recited the names of family members who had dealt drugs when they were growing up, or their own brushes with the juvenile or adult criminal justice systems. Bullying was common. Taken together, the hard-to-shake feeling of being vulnerable, exposed, or “at risk” was hardly the exclusive material of so-called delusions, but rather an unavoidable and long-standing reality of life. Psychosis typically replayed these themes, rather than introducing them to individuals who otherwise had no reason to fear for their lives or freedom. (See also Luhrmann, Padmavati, Tharoor, and Osei (2015) and Larøi and colleagues’ (2014) work on voices and culture.)

In our experience, many who have not personally experienced “voices” assume that this particular symptom, at least, is easy to accurately imagine or simulate: not all that different from the disembodied voice of a stranger talking a few feet away. When asked in detail about their experiences, however, only a sub-set of the “voice hearers” we have interviewed and worked with reported voices that took this form. Others described “felt presences” (the “voice” as a silent but locatable entity or organism, moving through the neck or head, or clearly situated in physical or somatic space) and still others told us that they “received messages without sounds” or “heard” images or emotions rather than words. More often than not, what set these experiences apart from more everyday “unbidden thoughts” was not their sound qualities but rather their utter foreignness. Several participants used the imagery of insertion: whether sounds, messages, or images, they felt as if these communications or thoughts had been forced into their minds or brains by some entity or organism, moving through the neck or head, or clearly described “felt presences” (the “voice” as a silent but locatable entity or organism, moving through the neck or head, or clearly situated in physical or somatic space) and still others told us that they “received messages without sounds” or “heard” images or emotions rather than words. More often than not, what set these experiences apart from more everyday “unbidden thoughts” was not their sound qualities but rather their utter foreignness. Several participants used the imagery of insertion: whether sounds, messages, or images, they felt as if these communications or thoughts had been forced into their minds or brains by some powerful external entity. Their own selfhood and autonomy had been violated.

For many, “voices” or other ostensible sensory hallucinations also blurred with experiences conventionally labeled “delusions” and defined, in conventional psychiatric texts, as “fixed, false beliefs.” Multiple participants, for example, described “hearing” others whisper bad things about them but noted that they were not sure if they were actually hearing anything or instead simply “knew” that others were directing negative sentiments towards them (or reading their minds, or trawling or tracking them). “Beliefs” in the end of the world, in multiple realities or parallel universes, in mind control, were virtually always grounded in the sort of fundamental existential and experiential alterations described above. “This world,” for example, may have taken on a phony or sinister quality; subtle qualities such as depth or solidity felt “off.” In some cases particular moods might hang over things—an unaccountable gloominess, for example, or markedly different “intensity.” The meaning of things multiplied or accelerated; everyday things or qualities such as gestures or the color of the shoes others were wearing on a train platform might mean something. Such meanings were not necessarily clear or transparent and multiple participants reported an almost painfully self-conscious process of trying to explain, rationalize, and/or “re-order” their experiences.

Asked about recovery and/or healing, few participants primarily credited either medications or therapy (or, for that matter, other identifiable psychiatric interventions). Instead, many described a lengthy process of learning to navigate, and work through or with, their experiences and the changes that had taken place both within themselves and in their lives and extended social networks. To heal, for many, was not simply to “get away from” (or suppress) voices or alternative realities, but to make peace with what had been lost and what gained, to establish (real or imaginary) boundaries between themselves and distressing external forces, or to more comfortably occupy a space in which their alteration of thought and perception could more comfortably co-exist with “everyday reality.” One middle-aged participant wondered aloud what the experience of early psychosis would be like if young people in the United States had shamans (or similar guides) they could turn to for help sorting through their experiences, claiming their fears, and modeling a path of judicious integration.

Asked, at various junctures, who they had discussed these same ideas with, the majority of participants did not or could not name anyone, though a handful—typically years down the road—eventually connected with peers or colleagues with similar experiences with whom they could finally share their stories. For most, however, healing was a lonely path, especially with respect to the work of meaning making. One of our participants eloquently described her process as follows:

> [Eventually] I kind of kicked the bio-psychiatric model out of my head. I mean I’m still in the process of getting it completely out; I have the internal psychiatrist, that’s like, “That’s talking crazy, Allison.” So, yeah, it’s like, “Shut up.” But I think that once I got rid of that paradigm, where my experiences were seen as wrong or the result of a bungle or flaw or screw-up, and actually allowed myself to give personally relevant, somewhat adventuresome but relatively responsible meaning (to them), [I started to heal]…Now, I feel like I have a wholeness to myself and my experiences and my thoughts and whatnot that is, ironically, a lot more coherent than when it was like “these experiences are not okay. This is shameful. This is weird.” It’s no longer scary now that I’ve just let myself be like, okay, this obviously—this is part of mind, this is part of my heart, this is part of the world…how can I make this work, “cause it’s not going away.”

**IMPLICATIONS**

Peer-reviewed publications typically leave minimal space for extended discussion of the implications and importance of particular findings. While we think the basic upshot of our work is relatively clear—clinicians and researchers must attend far more carefully to the messy realities and subjective experience of psychosis, and avoid imposing and projecting mostly inaccurate and oversimplified constructs onto it—a lot remains to be said.

In workshops on psychosis, the clinicians we have trained frequently report tremendous interest in more deeply engaging with client’s experience of psychosis, but nevertheless tremendous uncertainty as to how to go about this. Clinical training—whether nursing, medicine, psychology or counseling—generally fails to equip front-line practitioners with the confidence to pursue the sort of mutual dialogue...
that would, in theory, allow the meaning and complexity of psychotic experiences to emerge. Some clinicians have reported fears that they might “make things worse” for individual clients, and others fear of supervisors criticizing them for “collusion.” Attention to issues of identity, particularly in the more fundamental sense of the individual’s perceptual, emotional, and existential “sense of being” are also virtually absent from standard clinical training.

Talking to clients, on the other hand, and as echoed in Allison’s aforementioned comments, the negative consequences of clinicians failing to ask the questions that matter most, or to explore the often nebulous stuff of psychosis, takes center stage.” No one has ever asked me detailed questions about what I experience,” we have heard repeatedly, “no one has tried to understand how this has affected who I am, no one has listened to the complications, to the richness, to the good things as well as the bad.” Certain dimensions of experience, including links to personal trauma, sexual or erotic content, or “symptoms” that challenge established categories of psychopathology, appear particularly under-explored. Clients who feel misunderstood, in turn, all too often either psychologically or behaviorally disengage or withdraw. Opportunities for deeper bonding and deeper healing are lost.

The confidence with which textbooks, standardized psychopathology courses and trainers all too often describe or define psychosis, is certainly a major barrier to such engagement and to clinical capacity building more broadly. One of us, presenting to a large group of persons with primarily psychotic diagnoses in the community a few years ago, was deeply saddened when a woman raised her hand, very hesitantly at first, and asked to confirm if what we were saying was indeed that “voices without literal sound(s) were still legitimate symptoms”; yes, we responded, and then two other women in the room broke down in tears. “I’ve always been afraid to say this to my doctor,” one explained, “because the ‘voices’ are terrible, but I don’t actually ‘hear’ them in a literal way, and I was worried that he wouldn’t think they were real, would just say I was experiencing the same things everyone does.” Another reported that her therapist had informed her that there was “no such thing” as non-auditory voices and so she simply stopped correcting clinicians who asked if she “heard” things. It is clearly critical that, at a minimum, clinicians of all disciplines, discard such over-simplified and over-generalized assumptions and embrace the diversity and variation of actual “psychotic” experiences.

A second major point is that healing is hardly so simple as taking a pill, or completing a sequence of evidence-based therapy, or engaging in a psychiatric rehabilitation program. As those we have talked and work with repeatedly remind us, healing involves a much more complicated process of personal and cultural reckoning and reconciliation. Clients must learn to navigate not only fundamental changes in the way they occupy the world, but also changes that have pushed them to the farthest margins of social and cultural life (cf. Schrader, Jones, & Shattell, 2013). The stark realities of such fundamental cultural marginality (psychosis, we might recall, is often defined precisely by virtue of its supposedly culturally unshared and unshareable nature) present major challenges when it comes to establishing positive identities and regaining a sense of belonging. Jobs matter, education matters, “functioning,” of course, matters, but functioning can only be built on the more fundamental bedrock of deep personal and interpersonal mattering.

Our work is not the final word on anything, and it is not meant to be; we nevertheless see ourselves as sounding an alarm and asking—perhaps even demanding—that clinicians, researchers and community members start listening much more carefully to what it is that persons labeled with psychosis are actually experiencing, to the impact of these experiences on them—in both deep and superficial way—and to the importance of a process of personal meaning-making that goes well beyond the conventional ethos of illness self-management. Living life, for all of us, is much more complicated than that, and so is living psychosis.

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