Reconceptualizing Psychosis: The Hearing Voices Movement and Social Approaches to Health

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Abstract

The Hearing Voices Movement is an international grassroots movement that aims to shift public and professional attitudes toward experiences—such as hearing voices and seeing visions—that are generally associated with psychosis. The Hearing Voices Movement identifies these experiences as having personal, relational, and cultural significance. Incorporating this perspective into mental health practice and policy has the potential to foster greater understanding and respect for consumers/survivors diagnosed with psychosis while opening up valuable avenues for future research. However, it is important that a focus on individual experiences of adversity not supersede attention to larger issues of social and economic injustice. Access to appropriate mental health care is a human right; this article will argue that the right to health additionally extends beyond individual-level interventions.

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Introduction

The diverse phenomena gathered under the diagnostic umbrella of "psychosis" are often perceived as uniquely biological. In the public imagination, depression and anxiety are intuitive responses to adversity; indeed, it is commonplace to describe a situation as "depressing" or "anxiety provoking." Schizophrenia, on the other hand, connotes a kind of alien intrusion, wherein a person's humanity is first colonized and then inevitably eroded.[1] In this sense, understanding experiences like hearing voices as part of a spectrum of human reactions to our environment remains a frontier within the mental health field. Pioneering this understanding is the Hearing Voices Movement (HVM), an international grassroots project that challenges the traditional wisdom that these experiences are best treated as a biogenetic disease state.[2]

In contrast to the ravenous but impersonal pathology implied by a diagnosis of psychotic disorder, the HVM searches for the underlying *meaning* of experiences such as hearing voices or seeing visions.[3] This deliberately open-ended directive encompasses a range of beliefs; however, most scholarly work to emerge from the HVM invokes an ecological framework that situates voices in the context of a person's culture, life history, past and current relationships, socioeconomic status, and so on.[4] Stressors such as poverty, loss, and abuse are cited as potential loci around which voices might take root, and voices are assumed to be personally (and perhaps socially) significant experiences that are richly informed by and embedded in the external world, and can thus provide a valuable window of insight.[5] The HVM centers the knowledge of "experts by experience," those with lived experience of hearing voices, both as an emancipatory project and in recognition of the scientific value of qualitative and narrative explorations of voice hearing.[6]

In this article, I will draw on the principles of the HVM to argue for a rights-based, trauma-informed, and socially grounded approach to the diverse experiences constituting psychosis and, more generally, for a reexamination of psychosis as a diagnostic construct. This approach has practical implications for mental health service provision.

Access to safe, respectful, and effective care is a human right; unfortunately, the care available to people diagnosed with psychotic disorder may, at times, be none of the above.[7] At present, commonplace psychiatric interventions may be experienced as dehumanizing and (re)traumatizing.[8] The use of force and coercion in treatment settings appears to be especially harmful.[9] Additionally, questions remain about whether current "best practice" guidelines for the use of antipsychotics are beneficial or actively detrimental in the long term.[10] Outcomes for people diagnosed with schizophrenia have not improved in the last 50 years, despite medical advances, while the longevity gap between those diagnosed and the general population continues to widen.[11] Clearly, more appropriate and humane models of care for this population are warranted; research emergent from the HVM provides a roadmap.

The right to health, however, extends beyond the individual right to care. Social factors are closely intertwined with experiences of health and illness, and reducing inequality and exposure to violence on a larger scale is a critical aspect of the right to health.[12] The role of power and disempowerment in the lives of those diagnosed with psychotic disorder, I will argue, must remain a focus in building on the work of the HVM. Policies and therapies that fail to address ongoing structural and economic violence will inevitably replicate the same harmful logic: that mental distress is a matter of individual dysfunction, to be dealt with through (sometimes unwanted) individual-level interventions, rather than an understandable reaction to frightening, oppressive, and demoralizing circumstances. A non-pathologizing approach that remains attentive to larger issues of injustice is called for.

A note on terminology

In this article, I follow the terminological conventions of the literature I cite, while remaining agnostic toward the preconceptions underlying their usage. I approach diagnoses as *constructs*, with the understanding that, for example, research concerning "schizophrenia" may in fact capture

information about a wide range of phenomena cohered by cultural rather than intrinsic factors. It is worth emphasizing that while individual perspectives vary, many voice hearers reject a medical framing of their experiences. Thus, where referencing literature concerning self-identified voice hearers, I avoid clinical terminology.

I also employ the terms "psychiatrized," "Mad," "consumer/survivor," and "diagnosed with" to refer to, respectively, people whose experiences are labeled as psychiatrically disordered; people who self-identify as Mad and scholarship emerging from Mad Studies; people who have direct experience with the psychiatric system; and people who have received a particular psychiatric diagnosis. I consider these terms overlapping, but not interchangeable, while recognizing their complex history.[13]

Background

The origin of the HVM is attributed to conversations between Dutch voice hearer Patsy Hague and her psychiatrist, Marius Romme, which led to Romme and Hague appearing on television together to discuss Hague's voices and her theories about their significance; viewers who heard voices themselves were encouraged to call a telephone line.[14] The response was tremendous, with 700 individuals calling in response to the program, 450 of whom heard voices.[15] An open-ended questionnaire was distributed to gather firsthand accounts of how voice hearers coped with their voices, and, subsequently, a congress was organized in Utrecht, where 360 voice hearers gathered to share their experiences.[16] Following this initial flurry of interest, Romme and his partner Sandra Escher went on to spearhead further research gathering voice hearer perspectives, particularly on the origins of voices, relationships of voice hearers to their voices, and strategies for managing distressing voices. Notably, it became apparent that many people who heard voices had never been in contact with psychiatric services, nor did they feel the need to be.[17] Many voice hearers were also able to link their experiences to a larger social or traumatic context.[18]

Romme and Escher argued for the importance of an "emancipatory" approach to hearing voices, arguing for the establishment of groups where voice hearers could exchange ideas and experiences.[19] Thus, the HVN was born, first as a loose, grassroots collection of self-help groups, and later in the form of national chapters, gathered under the umbrella of the international organization Intervoice.[20] Simon McCarthy-Jones identifies the HVM as emerging from postmodern and postcolonial thought, wherein individuals are moved to take ownership of their own narratives and identities, and the present-day HVM remains explicitly concerned with the right of voice hearers to self-determination.[21] Blackman interprets the HVM as promoting the recognition and integration of parts of self, in contrast to the denial that characterizes biomedical approaches.[22] For its part, Intervoice describes the movement's core values as follows:

> [H]earing voices, seeing visions and related phenomena are meaningful experiences that can be understood in many ways; hearing voices is not, in itself, an indication of illness—but difficulties coping with voices can cause great distress; when people are overwhelmed by their experiences, support offered should be based on respect, empathy, informed choice and an understanding of the personal meaning voices have in someone's life.[23]

A number of methods of working with voices have emerged from the HVM.[24] It remains an essentially pluralistic movement, stepping outside of the bounds of pathology and meandering across disciplinary lines, exposing the entanglement and co-construction of social and biological realities in the process.[25] Consequently, I will employ an interdisciplinary approach in considering how the HVM can inform a reconceptualization of psychosis, by situating it in richly enmeshed biological, social, cultural, and political contexts.

Support for a social etiology of psychosis

Given that the HVM engages heavily with the social context of voices for the individuals who hear them, its proliferation has sparked clinical interest in cultural and relational models of psychosis. The

peer-reviewed journal *Psychosis: Psychological, Social and Integrative Approaches* was founded in 2009; in 2014, the British Psychological Society published *Understanding Psychosis and Schizophrenia*, a report outlining psychosis as shaped by and responsive to social factors.[26] The HVM is beginning to be cited as an influence in disciplines as ostensibly incompatible as computational psychiatry.[27] Meanwhile, a growing body of research has highlighted the need for clinicians, researchers, and policy makers alike to attend to the role of environment in the origin of psychosis.[28]

The cardinal significance of heredity in schizophrenia is now disputed.[29] However, psychiatric genomics research continues to be communicated in a misleading way to the public, contributing to the negative impact of genetic determinism on public health policy, resource allocation, and experiences of stigma.[30] It is therefore critical that what John Read et al. refer to as "a genuinely integrated bio-psycho-social model" of psychosis be foregrounded.[31] For instance, the link between poverty and schizophrenia is long established and continues to emerge as a risk factor in recent large-scale population studies.[32] Countering the argument that schizophrenia merely predisposes individuals to experience hardship later in life, parental socioeconomic status and socioeconomic status at birth both independently predict later diagnosis.[33] Others note that low socioeconomic status predicts a diagnosis of any mental illness much more than a diagnosis of mental illness predicts downward class mobility.[34] Unsurprisingly, low socioeconomic status of origin also appears to negatively affect prognosis.[35]

Poverty is just one facet of the panoply of social stressors now recognized as central to psychosis; other culprits include isolation, inequality, racial discrimination, food insecurity, and migrant status.[36] Recent reviews and meta-analyses likewise find a robust connection between childhood trauma, particularly abuse, and later psychosis.[37] A systematic review and meta-analysis by Thomas Bailey et al. further determined that childhood trauma is associated with the severity of psychotic symptoms, while a meta-analysis by Antonella Trotta et al. found an impact on their persistence.[38]

Addressing concerns about confounding variables, a recent birth cohort study confirmed that substantiated reports of child maltreatment predicted a later outcome of psychosis, including when substance use and childhood behavioral problems were controlled for.[39] The only psychiatric outcome more strongly associated with traumatic life events, in fact, appears to be post-traumatic stress disorder (PTSD).[40] Interestingly, a diagnosis of PTSD itself predicts the later development of psychosis.[41]

Mechanisms implicated in the relationship between adversity and psychosis are varied and include heightened stress reactivity, negative belief systems about the self and the world, a tendency to perceive events as externally controlled, and the learned anticipation of threat.[42] The deleterious neurobiological consequences of childhood trauma are long established and may likewise play an important role in later psychosis.[43] Other authors suggest that psychotic symptoms may represent traumatic intrusions, akin to flashbacks and other "re-experiencing" symptoms in PTSD, or result from the misattribution of trauma-related affects and memories.[44] In light of the latter, alongside the observation that the so-called Schneiderian symptoms characteristic of schizophrenia are also—and perhaps *more*—prevalent in highly dissociative individuals, dissociation has also been proposed to mediate the relationship between trauma and later psychosis.[45]

This latter approach has found popularity within the HVM. Eleanor Longden and Simon McCarthy-Jones, both prominently associated with the movement, argue that the distinction between auditory verbal hallucinations occurring in PTSD (attributed to dissociative mechanisms) and those occurring in schizophrenia is flimsy at best.[46] This perspective is bolstered by subsequent reviews finding evidence of a connection between dissociation and voice hearing across a range of diagnoses.[47] Further, there is some evidence that dissociation could mediate the relationship not only between trauma and later hallucinations but also between trauma and later delusions.[48] Integrative theories that draw together dissociation and psychosis as post-traumatic attempts to manage overwhelming or confusing memories, sensations, and affects

have therefore achieved some prominence, as I have elaborated on elsewhere.[49]

Participants in "hearing voices groups" are encouraged to engage their voices (among other techniques—there is, by definition, no singular prescribed method) as disowned parts of the self that contain difficult emotions, embody core beliefs about the self and the world, or represent the phantoms of past survival strategies.[50] Drawing in part on this legacy, psychotherapy for psychosis has gained some traction in the clinical world.[51] Trauma-focused interventions specifically have shown tentative but promising evidence of their effectiveness.[52] Indeed, the shift toward trauma-informed care is now recognized as a salient issue within the mental health profession generally, summarized as a "move from thinking 'What is wrong with you?' to considering 'What happened to you?'"[53]

Complicating the medical model

In light of the abundance of research linking adversity and psychosis, the difficulty in differentiating between psychotic and post-traumatic or dissociative diagnoses has become a concern.[54] Several authors have proposed a model of overlapping, and perhaps interrelated, continua of experiences.[55] Read et al. call for a "traumagenic neurodevelopmental model" of schizophrenia, while Błażej Misiak et al. advocate for what they call a "unified theory of childhood trauma and psychosis."[56] Others go further, underscoring the notorious unreliability and heterogeneity of psychiatric diagnoses generally.[57] Dimensional models, which avoid rigid diagnostic categories and make blurrier distinctions between "sickness" and "health," have resulted in the concept of an "extended psychosis phenotype" or "psychosis continuum."[58] For its part, the HVM takes a depathologizing approach to those experiences gathered under the term "psychosis," arguing that phenomena such as voices and visions fall on the spectrum of human diversity and need not be understood through a disease lens.[59] To many of the movement's proponents, applying the label of psychiatric disorder is seen as disempowering and instilling a sense of fear and hopelessness.[60]

Cultural psychiatry offers a helpful lens for understanding the complexity of drawing these lines. Psychiatric diagnoses are necessarily culturally bound, based on socially constructed ideas of what is "pathological" or otherwise aberrant.[61] For example, Ethan Watters documents the exportation of Western conceptions of mental (ill) health over the past century, while Suman Fernando criticizes the idea that a "global" approach to mental health is possible, given the vast range of valuable *local* perspectives on what mental distress looks like, how best to respond to it, and whether it can be understood through a framework of sickness versus health.[62] Cultural neuroscience, meanwhile, holds that culture is embedded in and enacted by our cognitive processes at every level, emphasizing that how we conceive of distress is shaped by the metaphors and idioms we are given to communicate it.[63] In the West, psychiatry has equipped us with an arsenal of "idioms of distress" that relies on the language of neurological disease states; however, it is hardly the only cultural vocabulary that exists to convey distress.[64]

Medical anthropologists are equally careful to point out that modern biomedicine's conceptions of a "normal" body (and by extension, a "normal" mind) are historically and culturally specific, and, as such, deeply political.[65] Others note the risk of imposing "medical imperialism."[66] This is particularly relevant in the field of mental health, which by its nature concerns highly subjective experiences.[67] Indeed, critics suggest that globalization has presented the two-pronged problem of a simultaneous exacerbation of factors underlying mental distress and subjugation of indigenous systems of knowledge for interpreting and managing it.[68] While a biopsychosocial approach to psychosis informed by the HVM's attention to trauma and adversity as root causes is undoubtedly a step toward a more nuanced understanding of mental distress, it remains critical to resist a new dogma that retains its inflexible, disease-based structure.

Medicalization as obscuring social realities

A grisly tradition of "biologizing social facts" exists

within psychiatry.[69] Concepts such as degeneration and drapetomania have historically justified racist and eugenicist political projects; the pathologization of responses by black Americans to oppression in civil rights-era America is theorized to have shaped the modern diagnosis of schizophrenia.[70] This attribution of social problems to genetic defects has a clear utility for ideologies that attempt to demonstrate the biological inferiority of particular demographics. However, the advancement of neoliberal values and policies likewise favors naturalizing inequality through the lens of biology, locating the suffering caused by *social* problems within *individual* bodies, which are perceived as self-contained and (ideally) fully independent.[71]

An environmental etiology of psychosis may dispel the specter of biological determinism, but the issue of *medicalizing* problems which may be better understood as social remains. Even a post-traumatic medical model risks eclipsing structural inequality and violence by focusing on how they manifest at the individual level, a process of contextual stripping-away that Howard Davis calls the "depoliticization of trauma."[72] This narrow view of trauma banishes public concerns to the private domain, tidily dislocating them from shared reality and ascribing the suffering of traumatized people to their own internal inability to cope.[73] As cautioned by the survivor-led activist collective Recovery in the Bin, as long as the onus lies on the individual to "recover" from the harms inflicted by systems of power far beyond their control, the workings of the latter remain obscured, and the material needs of the former go unaddressed.[74] Heidi Rimke refers to this sleight of hand as "psychocentricity," explaining that

> [p]sychocentricity dovetails seamlessly with the values of neoliberalism by giving the appearance that "normalcy" is desirable, concrete and attainable. From this perspective, personal success is marketed as readily accessible to everyone and anyone.[75]

It remains contentious, too, whether it is appropriate to treat post-traumatic reactions as dysfunctional. Bonnie Burstow argues that the symptoms of PTSD are often protective responses to genuine threat.[76]

Indeed, some of the aforementioned neurocognitive changes in maltreated children may be adaptations to living in a dangerous environment—adaptations that, in the short term, are beneficial.[77] For China Mills, despair and pain are "normal" reactions to unbearable circumstances, and reconfiguring these expected and necessary feelings as symptomatic of illness contributes to the perception of impoverished people and communities as "deficient."[78] This sense of deficiency pervades research that attempts to link PTSD to an individual lack of resilience or personal failure to use effective coping strategies.[79]

Lastly, it is important to bear in mind that attempts to divest individuals of trauma responses, including those that take on a psychotic guise, are not always welcome, warranted, or politically neutral. Kathryn Becker-Blease cautions clinicians to "reject those trauma-informed practices that leave individuals well-adjusted but inactive in the face of oppression and trauma" and warns that even the most ostensibly progressive of interventions can become "just a different way of labeling and managing" individuals.[80] Some disability scholars further emphasize the role of "madness as testimony": as Clementine Morrigan explains, so-called symptoms occurring in the wake of trauma may in fact be "acts of resistance to violence," "a means of sounding an alarm that something is very wrong."[81] In my own words writing for the BC Hearing Voices Network:

> the personal mythology of delusion offers a sanctuary: a domain in which we are free to speak about our injuries without the intrusion of outside perspectives. Society cannot or will not follow us into this magical-metaphoric thicket. Here, we are free to imagine and reimagine our experiences in ways that would otherwise be forbidden to us.[82]

Broadening the focus from "what happened" to "what is still happening"

Consumer/survivor initiatives have historically been subsumed and repurposed in less radical ways by the psychiatric institution.[83] In recent years, for example, attention has been drawn to the ap-

propriation of the "recovery narrative," which has divorced it from its activist origins.[84] Jasna Russo and Peter Beresford describe the balancing act that Mad scholars must perform "between exclusion and colonization," wherein all too often our voices are wrested away from us in service of institutions from which we are barred.[85] In light of this, it is important that insights derived from the HVM do not inadvertently reify exactly the structures and policies they are meant to critique. That is, a social understanding of psychosis must foreground society, and not sick or damaged individuals. Asking "what happened to you?" is an excellent start—but asking "what is still happening to you?" may be even more crucial.

After all, adversity has a cascading effect. Research consistently identifies a subpopulation of people who experience very high levels of trauma throughout the course of their lives; usually, these people are born into and live in poverty.[86] It stands to reason that often, at the point of engagement with mental health services, these same adversities will be ongoing. Indeed, Scott Stumbo et al. found that while a higher number of adverse childhood experiences predicted worse outcomes for people diagnosed with serious mental illness, it did so via the likelihood of having faced *recent* traumatic events.[87] Similarly, a systemic review and meta-analysis found extremely high rates of recent sexual and domestic violence among people diagnosed with serious mental illness—a sixfold increase from rates in the general population.[88] This kind of active victimization is routinely under-detected and overlooked in mental health settings.[89]

It is critical that discussions about the causes and significance of psychosis borrowing from the HVM not overlook the role of *present-day* economic injustice, gendered and racialized violence, and so on. As the concept of "continuous traumatic stress" put forward by Gillian Eagle and Debra Kaminer reminds us, "for many citizens of the world today, trauma exposure is both current and to be realistically anticipated in the future, rather than being past or post."[90] In these cases, conventional trauma therapies may not be appropriate, nor can ongoing distress justly be considered pathological.[91]

Regardless of geographical location or political climate, it is fair to say that many traumatized people who go on to be diagnosed as psychotic are, in fact, in real danger, and not merely troubled by a shadow of the past; research investigating pathways to and through homelessness, for example, commonly reveals histories of compounding adversity precipitated by poverty and abuse early in life and later culminating in a cycle of psychiatric hospitalizations, housing insecurity, and continued victimization.[92] While a trauma-informed approach to mental distress in this population is needed, it must ultimately also be a *political* approach that concerns itself with changing the present in addition to charting the past.[93]

Toward a social approach to mental health

The HVM has fueled a move toward new ways for voice hearers to reflect on and engage with their experiences, with promising implications for the provision of services for this demographic. However, the right to health is not limited to clinical settings, nor are services traditionally perceived as medical or psychotherapeutic the only means of ensuring mental well-being. Material safety and practical support with present day concerns, such as housing and food security, must remain a core focus for mental health professionals and policy makers. Asking that disenfranchised people and communities reinterpret their distress as the fallout of traumatic events is insufficient when the traumatic conditions are ongoing. Additionally, it is important to consider the appropriateness of medical approaches to a problem that relates not only to health care but to human rights issues and abuses in a variety of domains.

Recent insights in the fields of psychology, neuroscience, sociology, and anthropology (among others) have the exciting potential to coalesce with the HVM to establish a novel paradigm for understanding voice hearing, and perhaps mental health generally. Nevertheless, it is important to attend to the political scaffolding that undergirds how these developments are interpreted, communicated, and actualized in policy and future research, as

the nascent projects of "critical neuroscience" and "postpsychiatry" have attempted to foreground.[94] Further, a focus on the autonomy and self-definition of those accessing mental health services will be essential to avoid replicating existing patterns of disempowerment, which appear to be compounded for survivors of previous violence.[95] Efforts to integrate this respect for individual meaning-making and self-directed treatment with awareness of social context have already resulted in ambitious new models of mental distress, such as the British Psychological Society's Power Threat Meaning Framework.[96] Alongside the 2014 *Understanding Psychosis and Schizophrenia* report, the Power Threat Meaning Framework calls for a socially informed, rights-based approach, outlining necessary changes to clinical practices and mental health legislation, as well as to policies concerning economic, racial, and gender injustice. Centering consumer/survivor-led activism and organizing will be key to sustaining this transformation within and outside academia.[97] Moving forward, collaboration between a broad range of experts by experience and education can ensure that insights emergent from the HVM continue to guide understandings of health as a fundamentally social, cultural, and political process.

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