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## “Did I push myself over the edge?”: Complications of agency in psychosis onset and development

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**Objective:** To investigate the subjective experience of agency in the onset and early development of psychosis.

**Method:** We conducted 19 in-depth interviews with a sample of individuals with self-reported diagnoses of schizophrenia and/or affective psychosis. Interviews focused on participants' experiences of agency and control in the onset and development of positive psychotic symptoms. Interviews were coded and transcripts analyzed by service-user researchers.

**Results:** The majority of participants reported multiple ways in which they experienced their own agency or intentionality as involved in the initial onset of psychosis, in self-conscious engagement with symptom structure and content, and in their elaboration and development. For many, the moral implications of these felt experiences were considerable, at times leading to shame or guilt.

**Conclusion:** Clinical accounts often stress the imposed, involuntary experience of symptoms and onset. Our project suggests that at least a subset of subjects with psychosis instead experience themselves as partly or fully “responsible” for onset, and actively involved in the shaping and elaboration of positive symptoms. In both clinical practice and future research, we argue that such complications should be explored and grappled with rather than downplayed.

**Keywords:** first episode psychosis; psychosis onset; phenomenology; agency; subjective experience

Agency – or the subjective sense of control or authorship over a given action or behavior – is implicated in many areas of psychiatric research and intervention. Over the past two decades, clinical researchers, particularly those grounded in cognitive approaches to psychosis, have documented diverse ways in which service users can actively work with – and transform – distressing thoughts, feelings and perceptions (Bentall, Kinderman, & Kaney, 1994; ; Chadwick & Birchwood, 1994; Roe, Chopra, & Rudnick, 2004). Recent work in phenomenological psychiatry has also sought to bring together lengthy historical engagement with abnormal alterations of agency (such as thought passivity) and more holistic, person-centered approaches that emphasize the individual's active role in responding to these experiences

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(Nelson, Parnas, & Sass, 2014; Sass, 1992, 2014; Stanghellini, Bolton, & Fulford, 2013). Maher's (2006) theory of delusion formation is premised on the idea that service users actively work to make sense of initially strange or ineffable perceptual and/or atmospheric alterations. The literature on clinical insight has also repeatedly grappled with multi-dimensional forms of client intentionality, including self-awareness of symptoms, recognition of symptoms in others, and interpersonal recognition of interlocutors' reactions to the client's own symptoms (David, 1990; Wiffen et al., 2013).

Service-user researchers and activists have drawn attention to the politics of clinical and/or professional representations of psychosis, and the limitations of theory built around the third-person observation and interpretation of psychopathology (Corstens, Longden, McCarthy-Jones, Waddingham, & Thomas, 2014; Grant, 2010; Rose, 2008; Russo & Beresford, 2015). Historically, phenomenology's founding patriarch, Edmund Husserl (1991), repeatedly stressed the limitations of second- and third-person phenomenology, underscoring the difficulties inherent in the interpretation of *others'* interior mental experiences. Commentators have also noted the clinical literature's strong emphasis on psychotic pathology (and associated treatment), rather than clients' holistic experiences, including positive and/or spiritual aspects of voices and/or altered beliefs (Davidson, Stayner, Lambert, Smith, & Sledge, 1997; Woods, Romme, McCarthy-Jones, Escher, & Dillon, 2013). Agency, particularly in the sense of the agentic construction of psychotic experience (rather than self-driven agentic interventions aimed at reducing distress or "managing" symptoms), is arguably one such casualty of a body of academic work that has failed to adequately grapple with the internal complications of agency in psychosis.

## Background

### *Objectives*

In this paper, we describe a novel user-led investigation of the phenomenology of subjective agency in psychosis. The research protocol we followed was dialogic and paired each participant with an interviewer with lived experience of psychosis. Participants were encouraged to review emerging themes and all final coding and analysis was undertaken by researchers with first-person experience of psychosis. Our specific objectives were to better understand:

- (1) subjective experiences of agency leading up to and during the initial onset of psychosis and;
- (2) participant's accounts of their own active or intentional role in creating, developing and/or elaborating the content or structure of positive psychotic symptoms.

## Methods

### *Participants*

Participants were recruited through flyers, the Internet and at community field sites, as well as through word of mouth and clinician referral. Inclusion criteria were proficiency in English, aged 18 or older, and self-identification as experiencing (or

having experienced) psychosis. The project was approved by the primary investigator's ethics board and all participants completed a standard consent process.

Table 1 provides demographic information for our sample. While the sample included participants with a range of educational backgrounds, there was an unusually large number with graduate degrees including three doctoral students. The length of time since onset varied from one year to approximately three decades. All participants reported a schizophrenia spectrum diagnosis and/or bipolar with psychotic features; all had been prescribed (and most continued to take) antipsychotics.

### *Interviews and coding*

Interviews followed a semi-structured phenomenological protocol. The opening query asked participants to “describe what had happened since [she or he] first developed unusual experiences”. The interviewers followed up with questions clarifying participant's accounts and therefore could diverge significantly depending on the particular types of experience, and stories, each participant chose to tell (cf. Thomas & Pollio, 2002). Throughout the interviews, participants were asked about their perceptions of agentive involvement, even when discussing experiences not directly related to agency. For example, “to what extent did you feel that you had control over that?” Participants were given the opportunity to request follow-up interviews (three did so). Individual transcripts ranged from 23 to 85 pages.

Our analytic strategy drew on both grounded theory (Charmaz, 2014) and qualitative phenomenology (Thomas & Pollio, 2002). The first and third authors coded the transcripts independently. They then compared codes, and subsequently tested each other's codes. Once a point of saturation had been reached in the generation of new codes related to agency, the coders agreed on a final coding framework. After a round of trial coding (aimed at establishing reliability and consistency), the first author applied the coding frame to the full set of transcripts. Finally, coded passages were aggregated, discussed and collaboratively fashioned into the thematic categories presented in this paper.

Table 1. Demographics.

|   |    |
|---|----|
| <i>Age</i>  |    |
| 18–40   | 11 |
| 41–60   | 5  |
| 61+   | 4  |
| <i>Gender</i>   |    |
| Male  | 10 |
| Female  | 9  |
| <i>Ethnicity</i>  |    |
| Caucasian   | 14 |
| African-American  | 3  |
| Latino/a  | 1  |
| Asian   | 1  |
| <i>Education (highest level completed)</i>              |    |
| High school/GED   | 3  |
| Some college  | 4  |
| Undergraduate degree or currently undergraduate student | 3  |
| Master's degree or currently Master's student           | 6  |
| Doctoral degree or currently doctoral student           | 3  |

### ***Participatory methods and user leadership***

The project was service-user-led and employed multiple participatory techniques. In total, six different graduate students with personal experience were involved in some aspect of project development, coding and/or analysis. All participants were offered the opportunity to review and amend their transcripts and six elected to do so. One participant also offered a competing (alternative) analysis of the projects' initial analysis and two other participants provided critical written comments.

During interviews, participants were intentionally made aware of the shared experience of the interviewer(s). For instance, interviewers explicitly acknowledged the difficulty involved in articulating unusual experiences, which often helped encourage farther-reaching attempts to grapple with the limitations of available vocabulary. In many cases, participants continued to follow-up, send messages and/or seek out further dialog concerning their experiences long after the interviews were completed. While this material was not treated as formal data, these interactions inevitably informed developing analyses, in many cases leading the core coding teaming (first and third authors) to rethink their developing interpretations.

## **Analysis**

### ***Overview***

We group our analyses into two categories: (1) experiences of agency leading up to and during the initial onset of psychosis, and (2) experiences of agency involved in the subsequent production and elaboration of positive symptoms (primarily delusions and hallucinations). These analyses do not include experiences of agency present in the context of symptom self-management, a common theme that will be covered in future publications. Table 2 provides an overview of these categories along with examples of the experiences they encompass..

### ***Agency at onset***

Almost all our participants noted their difficulty identifying the precise point at which seemingly normal experiences – an active imagination, intense interest in religious ideas, or heightened anxiety – segued into psychosis.

Describing the events that led up to onset, many noted the continuity of themes or preoccupations that had started many years earlier with their (later) symptoms. Several participants, for example, described long-standing interests in religious or philosophical themes, and others in science fiction, interests that ultimately took on a much more extreme “reality” in the context of psychosis. These uncertainties regarding “point of onset” further compounded the subjective difficulty involved in determining the point at which a participant’s sense of “control” – actively studying Eastern philosophy, for example – transitioned to beliefs or “obsessions” that felt much more uncontrollable.

Several participants explicitly characterized this transition as involving a kind of rogue imagination during which dreams or preoccupations (gradually or suddenly) took on a life of their own. For instance, Andrew [M, mid-20s] speculated that psychosis could be understood as “a kind of imagination writ large.” Cecile [F, early 30s] similarly spoke of the gradual loss control over thoughts and fantasies:

Table 2. Primary coding categories with example themes.

|  |   |
|--|---|
| Agency at onset  | <ul style="list-style-type: none"> <li>• Difficulty discerning point of transition from prodromal to acute symptoms</li> <li>• Gradual loss of control over symptoms that initially felt more controllable</li> <li>• Fascination with nascent psychotic symptoms, in some cases leading participants to actively pursue them</li> <li>• Sense of having intentionally “pushed” oneself over the edge</li> </ul>  |
| Agency in the ongoing development and production of symptoms | <ul style="list-style-type: none"> <li>• Active interpretation and elaboration:             <ul style="list-style-type: none"> <li>○ Self-consciously framing or explaining experiences in particular ways</li> <li>○ Felt sense of “co-producing” or actively co-creating the content of specific delusions or hallucinations</li> <li>○ Consciously focusing on specific aspects of altered perception</li> </ul> </li> <li>• Physical or embodied agency:             <ul style="list-style-type: none"> <li>○ Exercising self-conscious physical or embodied control over symptoms; for example, by shifting position or posture or “moving” into a certain part of the body</li> </ul> </li> </ul> |

For a while, I’ve felt like that ... the beginning of a lot of my psychotic experiences were – imagining things, being able to control myself enough – but then, in the end, kind of losing control. [Even now] I [have to be careful to not] let my thoughts get away from me, because I can start thinking of things that aren’t even really existing or are not even there [and then, in my mind, they become real].

Many participants expressed suspicions that at least quasi-agentive motivational factors were at play in their eventual “loss of control”, including protective dissociation, “escape” or wish fulfillment. For some this involved uncomfortable experiences (or personal failures) that they consciously hoped to get away from, and for others fears about themselves (including their sexuality) that they felt they could not integrate or cope with. Still others described an ambivalent but often compelling interest in extreme or unusual experiences:

Andrew: It was actually kind of interesting ... the way that the delusions [and hallucinations] that I had were kind of teleological, in a certain sense. I feel like they weren’t random. In a lot of ways, they were kind of fulfilling my own preconceived thoughts, desires – not always, but in a lot of ways, they had a purpose.

Camilla: When I was 17, I became a lot more interested in schizophrenia and psychosis and then I found out that my father had extreme psychosis when he was around my – the same age. From the literature I was reading I got this idea that I’d be able to understand [his experiences] a lot better if I actually made myself psychotic.

Elizabeth described a somewhat more ambiguous give and take between her own desires and (delusional) forces she felt were controlling her during her earliest experiences. One evening (tagged as the beginning of her experiences of psychosis), she'd experienced an uncontrollable urge to cut her left hand with a razor, caused, she felt, by an external entity. The next morning, however, she continued to cut of her own accord: "It's paradoxical", she explained, "because you're being forced to cut your hand but on the other hand, at the same time, *you* want to see your blood."

Another recurring theme among a subset (5/19) of the participants was the sense that they had, in some form, "intentionally pushed [themselves] over the edge" (into psychosis). Penelope [F, early 30s], for instance, reported a slow descent into increasingly intense, but always ambiguous, alterations of perceptual experience. During this period, most of these experiences nevertheless felt strongly agentic to her – "there was no loss of insight", she explained, "it was like experiencing crazy things, but still knowing that they're crazy and that you could just as easily choose not to believe them." However, at a certain point, the ambiguity or "inbetween-ness" became so uncomfortable and that she felt compelled to "push herself" into the domain of the "unambiguously crazy":

Penelope: 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 ...?

### *Agency in the development and elaboration of symptoms*

As summarized in Table 2, we identified a range of ways that participants continued to experience themselves as agentially involved following initial onset. Virtually all these descriptions focused on the content or structure of what are generally referred to as "positive symptoms" – i.e. delusions and hallucinations.

### *Active interpretation and elaboration*

The most dominant theme in this category was the (often) inescapable sense of having to explain experiences that continued to feel ambiguous or unclear, even long after initial onset.

"It was all there, happening" as one participant explained, "but somehow not, because I wasn't putting any of it into words, weaving it together." "The delusions were like a puzzle or game", said another, "that I *had* to break down." For many participants, it was this active process of interpretation and naming that led particular symptoms to take on clearer and more enduring forms and meanings.

Similarly, several participants described the ways in which active processes of interpretation helped maintain the continuity of themes and content across episodes. For example, Maurice reported weaving together retrospective accounts of suspicious events at the beginning of each new episode:

Usually the way it works is, I'll think, "Well, here I just haven't been aware all this time of what's really going on, but now I know." Then there's this process by which I sort of start to evaluate anything that's happened in between, in light of these sort of ideas that I have, you know? People that I've known, conversations – really specific

conversations [that I've had] suddenly become very meaningful, and then they get sort of incorporated into this broader story.

In other cases, participants actually described the sense of having consciously “forced” their experiences into a more manageable schematic:

Penelope: I just [end up feeling] stuck trying and trying to figure it out, trying to articulate it better, trying to create some sort of conceptual framework in my own mind. I fail, and yet I can't just go back into consensual reality, so I'm just trapped trying to figure it out and make it “make sense.” *Forcing* things into a pattern.

For other participants, the tenuous boundary between controlled and uncontrolled imagination continued to color their experiences long after onset. Joe, explained that his delusions continued to carry a dual sense of both reality and imagination:

“With psychosis, the event actually happens, *even though* it's imaginary.”

Participants also frequently described an awareness that their experiences were not quite real, awareness which often heightened perceptions of active involvement:

Bob: I had sort of flashes of insight where I recognized, oh, that thought is ridiculous, and [then] sort of drift or slip back into it and be convinced of it once again.

Joe: I think I always could kind of realize that this was just something happening inside my head. It wasn't like thoughts were coming from outside me ... It was more all in my head. It was like “Well, what is going on inside my head and why am I remembering these things and why do I *look* for additional meaning?”

“Looping effects” were often present in these descriptions. Participants consistently reported that the more they focused on their symptoms (or symptom content), the more “real” or “tangible” these experiences seemed. For instance, several participants noted that the more they thought about their voices *as* voices, the more conventionally voice-like they came to seem. One participant described vivid mental images of burning people and buildings, that only with time and attention, took on the qualities of more “literal” visions (for example, appearing on the horizon even when not a conscious focus of attention). Others described a similar process with reference to content: the more they fixated on strangers talking at a party or in a cafe, for example, the more disturbing and self-referential their conversations came to feel, even though the participant could not hear what they were saying.

### *Physical or embodied agency*

Although delusions are often conceptualized as “beliefs” (at least some of the time with the implication that they are not especially embodied or sensory), virtually all our participants described their experiences of psychosis in richly embodied ways. Paranoia, for example, was frequently described less as the thought or belief that some entity was after the participant than the almost physical “sense” that the participant was being watched and followed or their personal space (and sometimes mind) “invaded”. In many cases, both voices (or other hallucinations) and “delusions” were assigned a physical location, often *within* the body or brain.



This sense of location and physicality frequently seemed to pave the way for agentive involvements that were also experienced as embodied or physical. For instance, some participants described either moving psychotic sensations or objects within their own body, or (internally) rearranging themselves:

Penelope: It's like I'm seeing it in my mind's eye what's going on inside my head and feeling it, but not in the same way that one would feel a literal sensation; it has a feeling-like quality, and I feel like I have some degree of control, like sometimes I can try push people out of – not completely out of my head, but to a different area of the brain or to a different area of the cavity in the skull when I'm thinking about it that way.

Matt: I could push my awareness into different parts of my head in order to access different parts of my self and be a different way and act a different way and feel a different way. I remember one time when I was [at a celebration] and there was a performing actor like a juggler. He called for volunteers. I wanted to go up on stage and impress [someone]. I pushed myself into the right side of my head, is how it occurred to me then, so I would be more outgoing.

Other participants described physical interventions *outside* the body. For some participants, this involved the erection of “magical” physical boundaries that could block certain experiences (such as demons or intrusive voices). For others, psychotic experiences might be mapped out in physical space – drawn or charted – and then physically rearranged or manipulated. For example, Camilla related her conviction that by (physically) breaking the lines on a mapped schematic of her delusions, she could fundamentally change them:

My delusions were ... these big networks and I would draw diagrams of them and I'd have hundreds of pieces of paper at my parents' house ... you'd just see huge pieces of paper of really crazy sort of word-map-looking things of words with lines between them. I thought that if I could somehow break those [that I could change them] – the delusions were like these connections I couldn't break and I wanted to break them down because I wanted to change [them].

### ***Postscript: Moral implications of felt agency***

One of our participants was so convinced that her sense of control over the onset of her symptoms meant that the experience was not “true” psychosis that, in response to an early draft of these analyses, she insisted that we not conflate her “intentional” experiences with those of individuals experiencing what she termed a (more authentic) “surprise psychosis”: “Was it the same experience as people who experience psychosis without actively seeking it?” she wrote, “I don't think it was. And it's largely for this reason that I do not feel I can be a voice for people with ‘surprise’ psychosis.” While she made this claim more boldly than others, however, several additional participants (all of whom had been hospitalized for schizophrenia) expressed concerns that their experiences were not representative of “real” psychosis. “It seems like I had too much control”, one stated; “if I'd really tried I'm sure I could have stopped it” reflected another.

The experiences of *other* people with psychosis, these participants appeared to think, were, unlike theirs, more passive and far less (or not at all) controllable.

Although we did not explicitly ask all participants whether they had discussed their experiences of agency with clinicians, those who mentioned such conversations (or their possibility) described either consciously omitting their concerns out of a sense of shame, or mentioning them briefly only to be met with swift reassurance that their symptoms and onset were “completely outside their control and not something they should ever blame themselves for”. For at least one participant, such reassurances had “only made [her] feel worse about it”. Overall, we felt that few of our interviews were free of at least undertones of moral tensions or concerns related to participant’s experiences of agency.

## Discussion

In this paper, we describe multiple ways in which participants experienced themselves as actively involved in the onset and subsequent development and elaboration of (positive) psychotic symptoms. These experiences of agency included a subjective sense of instigating onset (or the transition from prodromal to “full-blown” symptoms), actively elaborating or co-producing particular “delusions”, and influencing their structure through selective attention or active framing and naming, as well as various forms of physical or “embodied” control. Ambivalence as to participant’s moral responsibility for their symptoms and the broader ethical implications of such responsibility were also common.

### *Agency and the experience of psychosis*

With respect to the existing literature on psychosis, we view our findings as affirming certain threads of scholarship, and diverging from (or significantly complicating) others. For instance, the heightened reflectivity we describe seems highly consonant with the work of Maher (2006) and the phenomenological psychiatry tradition (Nelson et al., 2014; Sass, 2014; Stanghellini et al., 2013). Divergence was more evident with respect to contemporary cognitive approaches to psychosis, however. For instance, rather than “jumping to conclusions” or falling prey to tacit cognitive biases (e.g. Falcone et al., 2015), many of our participants laid out a painful and often protracted process of conscious interpretation and discernment. Doubts and skepticism were an integrated part of, rather than absent from, most participant’s descriptions of the elaboration process. Participants also conveyed considerable awareness (both in retrospect and at onset) of motivations and dynamics that led them to, in some cases, actively embrace their nascent (bizarre) experiences.

In our reading, such accounts foreground the extent of possible individual and cultural mediation between “raw” psychotic alterations of perception and cognition and the ways in which such alterations are described, interpreted and “made to matter” by any given individual. As one of our participants phrased it, the whole experience felt much more like a “co-production”: her sensations and perceptions were suddenly radically changed, but she was nevertheless actively involved in investing them with particular meanings, directing them in specific ways; naming and organizing them. A fuller understanding of the relationship between psychosis, self and “recovery”, our findings suggest, must move past a narrower focus on “pathology” and victimization and instead grapple with precisely these sorts of agentic ways – both positive and negative – in which clients fashion meaning of their experiences (cf Jones, Kelly, & Shattell, 2015).

### **Moral agency**

The personal moral implications of participants' experiences are rarely discussed in the scientific literature, in spite of their clear relevance to healing and recovery (cf Myers, 2015). As Callard and colleagues (2012) have noted in a rare study focused on the moral implications of genetic explanations of schizophrenia as experienced by family members, discourses that write out agency entirely (for instance, by attributing psychiatric disability exclusively to biology) likely underestimate the extent to which even those who ostensibly endorse such models nevertheless continue to feel at least some degree of personal "responsibility". We suggest that rather than ignoring such complications – and their personal and cultural stakes – we would do well to move away from polarized views that pit "total" agency against "total" passivity (tying moral responsibility largely, if not exclusively, to the former) and instead wrestle with the much more complex subjective moral experience of behaviors and symptoms which may have been (or still be) at times passively endured, somewhat controllable, sought after or refused; distressing *and* enjoyable.

### **Clinical implications**

Psychosis, our analyses underscore, is complicated; complications that force to the surface myriad important questions about personal identity and values and felt moral responsibility (Jones et al., 2015; Schrader, Jones, & Shattell, 2013). All too often, therapeutic approaches to psychosis ignore or circumvent these complexities in favor of a focus on reducing distress or meeting functional goals (such as getting back to work or school). The participants in our study, however, frequently described other sorts of struggles that the clinicians they interacted with seemed largely unprepared to address: what their choices and particular psychotic experiences said *about them*; how to draw the boundary between "them" and "their symptoms"; how to reconcile dominant social and clinical narratives of psychosis (i.e. as suffering or victimization) with a far messier internal experience.

### **Limitations and future directions**

Like all exploratory qualitative studies, our intent was not to produce generalizable knowledge. Instead, we offer our project as a modest contribution to what we see as an extraordinarily heterogeneous diagnosis and associated set of subjective experiences. Research with larger and more diverse samples would be needed to determine the overall prevalence of the experiences described here. Our sample is also idiosyncratic in various ways, including a high percentage of postgraduate participants, and, in tackling onset and early experiences, relied exclusively on retrospective accounts which may or may not map onto what it was that participants were actually experiencing when their psychosis began. With respect to methods, we cannot definitively answer the question of what impact service-user leadership and use of participatory methods may have had, although it seems plausible to conjecture that they deepened both the dialogs that unfolded during interviews and the analytic process that followed. Looking to the future, we hope that our project contributes to a push for greater attention to first-person experience, inclusion of researchers with such experience, and to the subjective complexities of psychosis.

### Disclosure statement

No potential conflict of interest was reported by the authors.

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