

# *Schizophrenia Bulletin's* First Person Accounts: Rethinking 'Patient Testimony' in the Medical Humanities

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Dr Angela Woods, "First Person Writing Four Way Reading," Birkbeck, December 2011

Marcia Murphy's "Grand Rounds" is a short First Person Account published in volume 33.3 of *Schizophrenia Bulletin*.<sup>1</sup> It opens with the description of her careful preparation for this intensive public performance: writing and revising her speech, rehearsing its performance, and wondering how it will be received by the audience of mainstream psychiatrists and medical students. When the day finally arrives, Marcia is ushered onto the stage of a 200-seat lecture theatre. Her story begins with an account of teenage depression, self harm, attempted suicide, psychotic breakdown, and a brief period of hospitalization. Sixteen years of suffering culminated in a near-fatal suicide attempt. And

"I then began to realize I had a decision to make. It was an intellectual choice, but became a matter of heart. I decided to commit myself to Christ. This decision and the events that followed transformed my life. At this time, I also began a new antipsychotic called Risperdal—"

"Risperdal is a good medication. Maybe your life turned around because you were started on this," Dr. Chapman interjected.

"I agree it's a good drug, but not a cure-all. I have a friend on heavy doses of antipsychotics, including Risperdal, and she still hears voices and has other severe problems. I believe my condition improved because of the combination of Risperdal and my religious faith."<sup>2</sup>

Marcia is thanked for her participation and escorted from the lecture theatre. Using printouts of the formal presentation, and verbal reports from the participants, Marcia describes how the Ground Rounds continue as a closed professional debate about the role of religious faith in recovery from psychosis.

Authors and audience, the importance of the contextual and discursive frame, questions of authenticity and authority in the ‘telling’ of schizophrenia: Marcia Murphy’s First Person Account brings to the fore many of the key issues of this paper.

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*Schizophrenia Bulletin* brings psychiatrists, neuroscientists, psychologists, geneticists and assorted other schizophrenia researchers into dialogue. In 1979, ten years after its launch, *Schizophrenia Bulletin* started to include among its experts people with a subjective experience of schizophrenia through the regular “First Person Account.” The stated aim of publishing these short pieces – of which Marcia’s is a compelling example – is to deepen researchers’ insight into “the issues and difficulties confronted by consumers of mental health care,” and to respond to “a continuing need for experiences to be shared among mental health professionals, families, and current and former patients.”<sup>3</sup> The 109 First Person Accounts published over the last thirty years have been written by mothers, sons, psychiatrists, sisters and sufferers; they have been works of activism as well as anonymous confession; they have functioned as forms of professional development as well as personal catharsis.

My research into this archive has convinced me that reading *Schizophrenia Bulletin*’s First Person Accounts must start with a serious and detailed inquiry into the nature of such an endeavour. How can and should we read (understand, interpret, contextualise, draw connections between, and even use) these First Person Accounts? What would it mean if we were to read them as testimony? And who do I, as someone from a literary and cultural studies background working in the medical humanities, mean by ‘we’?

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While there is no shortage of work in the medical humanities on ‘illness narrative,’ there is still, in some quarters, an unwillingness to think critically about ‘patient testimony’;<sup>4</sup> to assume, for example, that *Schizophrenia Bulletin’s* First Person Accounts provide “the mechanism for *direct access* in coming to know the life of persons, their circumstances, and the meanings they associate with a life of persistent and enduring mental illness.”<sup>5</sup> It is this sense of transparency, of unmediated access to ‘inner’ life, which I think must be strenuously resisted.

### Genre

Returning to Marcia Murphy’s “Ground Rounds” we can see that it functions as a kind of double testimony – it records, for the benefit of a clinical audience, the experience of being called upon to present one’s “recovery story” as a form of clinical evidence. The narrative dramatizes tensions inherent in the dialogue between patients and psychiatrists: Marcia is asked to tell her story on the condition that it conforms to the strict protocols of the psychiatric interview, but is prohibited from hearing, much less discussing, the official clinical story of her experience, her case history. The clinical gaze – here literally embodied by the dozens assembled for the Grand Rounds – fixes her as an object of attention, analysis and instruction; but it is precisely by being summoned as ‘the good patient’ that Marcia is able to disrupt the conventions of the role. “Will I be able to communicate my view of recovery? Will I be allowed to say what is important to me? Will they hear and be convinced by my story?” As she has over twenty-five years of experience of psychiatric services, these are not idle questions. Overcoming her anxiety and apprehension, however, Marcia succeeds in telling her story, which is to say that she succeeds in challenging the authority of her interviewer, and of the dominant biomedical account of schizophrenia, by insisting on the importance of religious faith in her recovery from psychosis.

As a long-established medical practice, the Grounds Rounds<sup>6</sup> is both an occasion and a set of conditions for a very specific kind of storytelling. First, it requires that the patient take up a position of clinical scrutiny and detachment with respect to her own experiences: if it is to have pedagogic value, then suffering, assessed for its clinical relevance, must be presented in a manner which allows no manifestation of distress. The patient is called to bear witness to her experience, but she is not the final authority on its meaning; rather, it is the audience, and specifically the presenting psychiatrist, who will determine the way in which it is to be interpreted. For the patient, the event is singular; for the clinicians, it is repetition – the person before them is an iteration of ‘the patient,’ and for the ritual to be enacted successfully, the distinctive features of an individual case must be comprehensible within the existing horizon of expectation.<sup>7</sup>

The logic, or genre, of the Grand Rounds, has much to offer an analysis of *Schizophrenia Bulletin's* First Person Accounts. As John Frow reminds us: ‘No speaking or writing or any other symbolically organised action takes place other than through the shaping of generic codes.’<sup>8</sup> For Frow, genre ‘is neither a property of (and located ‘in’) texts, nor a projection of (and located ‘in’) readers; it exists as a part of the relationship between texts and readers’ as a ‘shared convention with a social force.’<sup>9</sup> Preceding and structuring the substantive content of a text, genre constrains, structures and shapes meaning and value, it projects a specific kind of ‘world,’ and, perhaps most importantly, it produces specific effects of truth and authority.<sup>10</sup> Although no explicit editorial policies around First Person Accounts were ever developed or implemented,<sup>11</sup> as we will see the First Person Accounts follow clear organisational, rhetorical and thematic rules which shape what can – and what can’t – be admitted (in the textual equivalent of the grand rounds) as the evidence of ‘experts by experience.’<sup>1213</sup>

According to Frow, it is the “‘immaterial” categories of time, space, and enunciative position’<sup>14</sup> which formally organise the projected world of a genre. In the case of First Person Accounts of schizophrenia this projected world is one of conventional realism – the narrator and the author are

presumed to be one and the same; time is linear; space seems consonant with conventional expectations. Although it appears mundane, this point is actually highly significant when we reflect on the fact that schizophrenia can produce very real *changes* to people's experience of temporal, special, corporeal and interpersonal experience. In all First Person Accounts of schizophrenia I have studied, only one author departs from the genre's conventions of realism by discussing, among other things, her cloned existence across temporal fields.<sup>15</sup> That means in 108 of the 109 accounts the enunciative position is predicated on the exclusion of anything, even the fictional or fanciful, which could be construed as symptomatic.

The second organising dimension in Frow's account of genre is the 'structured situation of address' between author and reader, a structure that refers to the power relations between speakers as well as the effects of 'credibility, authority, and emotional tone' created by these relations. Conscious of the need to persuade their clinical and scientific readers, the author-narrators of *Schizophrenia Bulletin's* First Person Accounts establish their authority and authenticity by borrowing the rhetorical structures of case history and academic argument.<sup>16</sup>

Frow defines the '*thematic content* of a genre ... as the shaped human experience that a genre invests with significance and interest.' The shaped human experience that First Person Accounts invest with significance and interest is, of course, that of schizophrenia. Or is it? In fact, this genre is actually less concerned with the experience of schizophrenia per se than it is with the experience of recovering from, understanding and coping with that experience. The distinction is subtle but important, as it leads to the question: is this 'recovery writing' 'illness narrative' or survivor testimony?

## Testimony

In the mental health context, self-proclaimed survivors<sup>17</sup> adopt the term because they believe they have survived mental distress, social stigma and psychiatric services. As Mark Cresswell has shown,<sup>18</sup> “‘Survivor’ knowledge,” challenges the ‘official’ knowledge of psychiatry by emphasising “individual experience, the traumas of the life-course, and the personal testimony of the survivor as itself expert data.”<sup>19</sup> Testimony, here, is not simply self-advocacy, or self-narrative, for:

In order to grasp the specificity of testimony as a truth-claim, we have first to see it as a performative discourse, not as, say, an expression of autobiographical fact. In testimony, the survivor does not express her unique historical knowledge, which the receiver accepts as a ‘given.’ Rather, testimony aims to bring into being a state of affairs in which the survivor’s truth is witnessed as an event about which ‘something ought to be done.’ In ‘surviving’ the performance of testimony, the receiver is simultaneously called upon to do something about it. That is testimony’s political point.<sup>20</sup>

To read *Schizophrenia Bulletin* First Person Accounts as testimony would be to recognise not just the legitimacy of a certain form of knowledge, but, more radically, to be called *to* a particular form of (anti)psychiatric politics, and called *upon* to do something as a consequence. As we have seen in “Grand Rounds,” writers like Marcia Murphy certainly do ‘speak back’, challenging the psychiatric status-quo, asserting the validity of the recovery movement. But is whoever is listening, or reading, moved to act differently as a result?

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Medical anthropologist Sue Estroff has argued that more must be done to do due diligence to the qualitative data generated by ‘consumers/survivors/ex-patients’ in order to overcome issues of invisibility, invalidation and incompatibility. I would like to question whether viewing First Person Accounts as qualitative data best recognises the intentions or serves the interests of their authors. As I have tried to show in this paper, we in the medical humanities and allied fields need to think more critically about the nature of the First Person Account, its status *as* text, its genre, its historical antecedent in the case history, its relationship to a particular phenomenology or set of experiences, and its relationship to particular political projects. With all the good will in the world, treating them as transparent simply will not get us there.

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<sup>1</sup> Marcia A. Murphy, "Personal Account: Grand Rounds," *Schizophrenia Bulletin* 33, no. 3 (2007).

<sup>2</sup> *Ibid.*, 659.

<sup>3</sup> Editors' preface to Martha DuVal, "First Person Account: Giving Love . . . And Schizophrenia " *Schizophrenia Bulletin* 5, no. 4 (1979).

<sup>4</sup> Hayne and Yonge, for example, in their analysis of forty First Person Accounts identify 'four existentials' through which to interpret the lifeworld of chronic mental illness – corporeality, spatiality, relationality, temporality. Rene Geanellos uses 'Gadamerian hermeneutics' to study 19 First Person Accounts, identifying 1 meta-theme, 4 themes, 18 sub-themes and 3 lessons in the process Yvonne Hayne and Olive Yonge, "The Lifeworld of the Chronic Mentally Ill: Analysis of 40 Written Personal Accounts," *Archives of Psychiatric Nursing* 11, no. 6 (1997); Rene Geanellos, "Adversity as opportunity: Living with schizophrenia and developing a resilient self," *International Journal of Mental Health Nursing* 14(2005). Perhaps the most interesting of these is medical anthropologist Sue Estroff's article, discussed towards the conclusion of this paper Sue E Estroff, "Subject/Subjectivities in Dispute: The Poetics, Politics, and Performance of First-Person Narratives of People with Schizophrenia," in *Schizophrenia, Culture, and Subjectivity: The Edge of Experience*, ed. Janis Hunter Jenkins and Robert John Barrett (Cambridge: Cambridge University Press, 2004), 284.

<sup>5</sup> Hayne and Yonge, "The Lifeworld of the Chronic Mentally Ill: Analysis of 40 Written Personal Accounts," 314, my italics.

<sup>6</sup> For an illuminating discussion of Emil Kraepelin's presentation of a patient diagnosed with dementia praecox, see R D Laing, *The Divided Self: An Existential Study in Sanity and Madness* (London: Penguin, 1990).

<sup>7</sup> Robert Eaglestone, *The Holocaust and the Postmodern* (Oxford: Oxford University Press, 2005), 38.

<sup>8</sup> John Frow, *Genre* (London and New York: Routledge, 2006), 10.



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<sup>9</sup> Ibid., 102.

<sup>10</sup> Ibid., 73.

<sup>11</sup> Private correspondence

<sup>12</sup> Angela Woods, "Mind the Gap: Subjective and Scientific Perspectives in Schizophrenia Bulletin," 13th International Network of Philosophy and Psychiatry conference: Real People: The Self in Mental Health and Social Care, Manchester, University of Central Lancashire in association with European Network of (ex-)Users and Survivors of Psychiatry, June 2010; Angela Woods, "Emotion, Narrative and Schizophrenia Bulletin's First Person Accounts," invited seminar in the Emotions and Feelings in Psychiatric Illness (AHRC-funded network) major conference, Durham University, September 2010.

<sup>13</sup> There is nothing exceptional about this observation, indeed, it could equally apply to any kind of 'illness narrative' or 'patient testimony', but the topic has been all too frequently ignored in the medical humanities.

<sup>14</sup> Perhaps the exception here is in the family accounts, where a different politics of legitimacy is at play.

<sup>15</sup> K. Pushpa, "Schizophrenia—A Victim's Perspective," *Schizophrenia Bulletin* 35, no. 1 (2009).

<sup>16</sup> For example, in telling their stories it is not uncommon for authors to address psychiatrists and mental health policy makers directly, footnote relevant texts and provide a range of factual examples in support of the point they wish to make.

<sup>17</sup> Peter Campbell, founder of the mental health advocacy group Survivors Speak Out, explains that 'survivor' was taken up in the UK "partly because we survive in societies which devalue and discount our personal experiences and perceptions. But...chiefly because we have survived an ostensibly helping system which places major obstacles across our path to self-determination." Peter Campbell, "A survivor's view of community psychiatry," *Journal of Mental Health* 1(1992).

<sup>18</sup> Drawing on the work of Shoshana Felman and Dori Laub, *Testimony: Crises of Witnessing in Literature, Psychoanalysis, and History* (New York: Routledge, 1992); Cathy Caruth, ed. *Trauma: Explorations in Memory* (Baltimore and London: Johns Hopkins University Press, 1995).

<sup>19</sup> Mark Cresswell, "Psychiatric "survivors" and testimonies of self-harm," *Social Science and Medicine* 61(2005): 1669.

<sup>20</sup> Ibid., 1671-2.