

Rethinking "Patient Testimony" in the Medical Humanities: The Case of *Schizophrenia Bulletin's* First Person Accounts

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Illness narratives are the object *par excellence* of classical medical humanities enquiry. Thanks in part to the wider 'narrative turn' in the humanities and social science (Bamberg), interest in narratives of/and illness has been growing steadily across a number of fields (Woods, "The Limits of Narrative"), including medical anthropology (Mattingly and Garro; Littlewood), medical sociology (Frank, *The Wounded Storyteller*; Atkinson "Illness Narratives Revisited"), and the philosophy of psychiatry (Fulford et al.). While the medical humanities draw energy and insight from this work, they are perhaps distinctive in bringing social-scientific and literary-philosophical approaches if not together then at least into conversation. Medical humanities researchers with training in the social sciences typically view illness narratives as data to be solicited through interviews and then transcribed, 'coded' and analysed using rigorous methodologies, many of which are aided by sophisticated computer programmes. As the field widens to include work that is more critically and politically engaged (Atkinson et al.; B. E. Lewis), temporal and spatial situatedness, and the complex interplay between 'individual' and 'collective' narratives of illness (Atkinson and Rubinelli), are also coming into focus. A second stream of medical humanities researchers trained in literary and cultural studies approach the study of illness narrative from a different perspective and so with different tools. Here, textual and intertextual, aesthetic and historical detail come sharply into focus, with close-readings of lengthy and polished autobiographical, biographical and fictional accounts of illness teasing out the complexities of these projected worlds (Belling; Ingram et al). Where these divergent approaches to illness narrative might otherwise remain largely indifferent to each other's existence, their intersection in the field of medical humanities affirms shared interests in treating the messy and complex subjective experience of illness as something distinct from the biological functioning of disease, and so in ensuring that these experiences and the ways we come to communicate them are given the recognition they deserve.

Mental illness and distress present a particular set of complications for medical humanities work on illness narrative (Woods, "Beyond the Wounded Storyteller"), and nowhere is this more obvious than in the case of schizophrenia. Schizophrenia names some of the most profound transformations in human experience (Sass, "Self and World in Schizophrenia"; Kean, "Silencing the Self") even if its status as illness, disease, disability or diagnostic label is still strenuously debated.¹ The constellation of schizophrenic symptoms includes experiences of depersonalization and derealisation, hallucinations and delusions, and disorders in the realms of perception, sensation, cognition and emotion. Schizophrenia affects at least one per cent of the global population (Metzl x-xi, 187-8), and yet with the exception of a handful of much-celebrated autobiographies (Schreber; Renee; Greenberg; Saks), narratives of schizophrenia are conspicuous by their absence from public discourse. One explanation for this is that schizophrenia has been construed as eliding, resisting, or opposing narrative. The idea that schizophrenia is somehow 'anti'-narrative has developed across five domains: (i) in psychiatry, where the concept of schizophrenia is, as Barrett has argued, profoundly associated with dementia, degeneration and

deterioration, states from which no coherent storytelling or meaning making is considered possible (Barrett, "Degeneration"; "Disintegration and Division"); (ii) in neuropsychology, through studies investigating schizophrenia's assault on the cognitive and affective underpinnings of narrative capacity (Gallagher; Gruber and Kring);² (iii) in the philosophy of psychopathology, particularly in work focussing on the breakdown in narrative identity and the dialogical self (Lysaker and Lysaker; Phillips; Thomas; Mackenzie and Poltera); (iv) in an aesthetic realm, where the 'mad narratives' or anti-narratives of schizophrenia have been celebrated for their failure to conform to the humanist conventions of either nineteenth-century realism or literary autobiography (Sass *Madness and Modernism*); and (v) in the socio-political domain, wherein stigma and outright discrimination have been seen to muffle if not completely silence those with stories of schizophrenia. With this in mind, the analysis of schizophrenia narratives – whatever these might be – acquires some urgency as a medical humanities undertaking, especially if the field is to break new ground in achieving the moral and political objectives of bringing first-person perspectives of health and illness to the fore.

Such an undertaking is, however, fraught with difficulties, especially for the researcher who refuses to regard narratives as mere objects of analysis. Where, then, to begin? This article addresses arguably the most prominent – if still desperately under-researched – archive of schizophrenia narratives: the "First Person Accounts" of *Schizophrenia Bulletin*. *Schizophrenia Bulletin* was founded by psychiatrist Loren Mosher – then chief of the US National Institute of Mental Health (NIMH) Centre for Schizophrenia Studies – in 1969. Today, it is one of the highest ranked academic journals publishing scientific research on psychosis. Interdisciplinary by necessity, the journal sees itself as engaged in acts of translation across the psychiatric field, bringing neuroscientists, clinicians, psychologists and geneticists into dialogue. In 1979, ten years after its launch, *Schizophrenia Bulletin* started to include among its experts people with a subjective experience of schizophrenia, publishing short pieces with the twin aims of deepening researchers' insights into "the issues and difficulties confronted by consumers of mental health care," and responding to "a continuing need for experiences to be shared among mental health professionals, families, and current and former patients" (qtd. in DuVal 631). Of the 119 First Person Accounts published over the last thirty three years, close to three quarters were written by ex/patients, the remainder by family members; twice as many authors identified themselves as women compared to men;³ seventeen people chose to publish anonymously; two withdrew their accounts following publication; and almost one quarter of authors worked or had worked in some aspect of mental health services.

This article does not offer the kind of in-depth textual reading of these accounts befitting of a more conventional literary inquiry, nor will it undertake a comprehensive 'coding' of these narratives to identify their key themes and variations. Indeed, what follows is less directed towards content than towards the enterprise of analysis itself; the question posed is deceptively simple, but no less urgent for being so. It is: how should these First Person Accounts be read? The normative thrust of this question is of particular interest when writing for and from a field which includes on the one hand those with a strong investment in positively influencing the practice of healthcare, and those who on the other have debated questions of reception, reader response, and authorial authority for over half a century. "By whom? In what context? And for what purpose?" are questions that must also be asked. With the overall aim of laying the conceptual groundwork for future academic analyses of this archive, this article proceeds through three linked discussions. Part

one addresses the paratextual dimensions of the First Person Accounts and the editorial policies shaping their publication. Part two explores the nature of the contract implied between author and reader in what I call a 'genre of insight.' After a narrative interlude, the final section of this article presents four possible models or modes of reading the First Person Accounts and asks what consequences and commitments arise from their adoption.

I. Paratext and Policies

Medical anthropologist Sue Estroff's "Subject/Subjectivities in Dispute: The Poetics, Politics, and Performance of First-Person Narratives of People with Schizophrenia" is one of very few articles to address the *Schizophrenia Bulletin* archive explicitly (see also: Geanellos; Hayne and Yonge). Considering a range of sources, including personal correspondence challenging the legitimacy of her research, Estroff argues 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 (Estroff 283). This is an important and commendable goal and Estroff's call for more research in this area should certainly be supported, provided that one widespread assumption is overcome. This is the idea, articulated most clearly in the work of Yvonne Hayne and Olive Yonge, that published first-hand 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" (Hayne and Yonge 314) [my emphasis]. Such views are alarmingly common across the medical humanities, where there is a tendency to bracket literary studies' sophisticated accounts of the nature of representation and textual production, while at the same time ignoring warnings by sociologists that "We sell short ourselves and the possibility of systematic social analysis if we implicitly assume that autobiographical accounts or narratives of personal experience grant us untrammelled access to a realm of hyperauthenticity" (Atkinson, "Narrative Turn or Blind Alley?" 341). A more sophisticated approach to the study of illness narrative would see the critical convergence and mutual invigoration of social-scientific and literary perspectives, taking as its point of departure the idea that there is nothing natural or self-evident about narrative. In the case of the published narratives in *Schizophrenia Bulletin*'s First Person Accounts, such an approach would also entail paying close attention to the textuality of the text – its status as writing, published in a specific format, for a specific readership.

The paratext, in the now classic formulation of Gérard Genette, consists of all those textual and material elements which frame a literary text. From the title of a work to its typography, from the author's name to the accompanying information about the series to which the work belongs: the paratext exists, in the words of Philippe Lejeune as "the fringe of the printed text which, in reality, controls the whole reading" (qtd. in Genette 2) Attending to the paratext of *Schizophrenia Bulletin*'s First Person Accounts prompts recognition of what makes this collection of illness narratives so distinctive, namely, the scholarly context in which it appears. If typographically, these short prose pieces of between two and five pages are indistinguishable from the research articles they accompany, a close inspection of other elements of the paratext shows that they have been used to establish and police a distinction between 'subjective' and 'scientific' accounts of schizophrenia.

The series was launched in 1979 with the following editorial statement, printed in bold at the beginning of a piece entitled "First Person Account: Giving Love...and Schizophrenia":

The article that begins below is the first in a series of personal accounts to be published in the *Schizophrenia Bulletin*. We hope that mental health professionals – the *Bulletin's* primary audience – will take this opportunity to learn about the issues and difficulties confronted by consumers of mental health care. In addition, we hope that these accounts will give patients and families a better sense of not being alone in confronting the problems that can be anticipated by persons with serious emotional difficulties. Although there are a number of books and articles describing the personal experiences of patients and families with mental disorder, we believe there is a continuing need for experiences to be shared among mental health professionals, families, and current and former patients.

We welcome other contributions from patients, ex-patients, or family members. Our major editorial requirement is that such contributions be clearly written and organised and that a novel or unique aspect of schizophrenia be described, with special emphasis on points that will be important for professionals. Clinicians who see articulate patients, with experiences they believe should be shared, might encourage these patients to submit their articles to the *Bulletin's* new section, First Person Accounts.—The Editors. (qtd. in DuVal 631)

These two paragraphs create a discursive space which had not previously existed in mainstream clinical literature, a space which seeks explicitly to bring together two distinct sets of interests (the education of clinicians in “the issues and difficulties confronted by consumers of mental health care” and the provision of support to persons all too familiar with such issues). Particularly striking is the insistence upon clarity, originality and clinically relevant ‘take-home’ messages. This is at once an invitation for future contributors to adopt a style congruent with the conventions of academic writing, and, as this article goes on to discuss, a caution against the submission of anything which could be classed as ‘mad’ writing.

Reproduced with only minimal amendments until it was condensed into a single paragraph, the editorial introduction was for twenty-five years a consistent feature of the series and, alongside the naming of the narratives as such, the clearest paratextual assertion of the singular status of the First Person Account within a scholarly context. Explanatory notes on authorship also play their role during this period. In some cases, these short biographies depart from academic conventions by asserting the credentials of the author-as-life-writer alongside those of the author-as-mental-health-expert:

Barbara A. Turner is the single parent of three boys. She has worked with others with mental illness since 1984 and is currently with Places for People in St. Louis, MO. She has written several articles about her views and experiences as a person with schizophrenia and as a mental health professional. (Turner 650)

In others, degrees of anonymity are preserved (as when the author is to be contacted care of their psychiatrist (O'Neal)), and defended:

Author's note: After careful consideration, I have decided to publish this article anonymously, in the hope that by doing so, I will protect my family, my friends, and myself from any further embarrassment and discrimination. Protection against stigmatization is needed because our society does not feel "safe" for those of us who have been hospitalised for mental illness. As a former patient and employee of the National Institute of Mental Health, I am hopeful that this article will serve as a catalyst for needed change. ("First Person Account: Life after the Funny Farm" 544)

The paratext in all these instances makes authorship conspicuous, one might even say 'personal'; it is a frame which serves to assert a kind of authenticity distinct from that implied by the titles and institutional affiliations of the scientific contributors.

In 2005, Oxford University Press took over the publication of *Schizophrenia Bulletin* from the National Institute of Mental Health (NIMH) and all this changed. Gone was the editorial introduction, the notes on authorship and the inclusion of "First Person Account" in the title. Once located at the very back of the journal, as though an afterthought, or curiosity, the series now introduces the substantive matter of each issue. Genette writes that

Although we do not always know whether these [paratextual] productions are to be regarded as belonging to the text, in any case they surround and extend it, precisely in order to *present* it, in the usual sense of the verb but also in its strongest sense: to *make present*, to ensure the text's presence in the world, its "reception" and consumption. (1)

In the absence of any further editorial policy pertaining to the series,⁴ how are changes in the paratext of *Schizophrenia Bulletin*'s First Person Account – changes in the way that narratives of illness and recovery are 'made present' to the journal's readership – to be interpreted? Have the views and values expressed in the initial editorial statement become so unremarkable that no further rationale is required, or would it be more accurate to say that far from being absent or invisible, they are present, still, in shaping contours of an emerging genre?

II. Genre, Authority and Insight

The call to consider genre here goes beyond the cataloguing of sub-types of First Person Account. Certainly it is possible to distinguish, for example, life-narratives emphasising recovery and deliverance from psychosis; second-person accounts written by family members; philosophical investigations of "The Paradox of the Self and Suicidal Behaviour in Psychosis" (Kean, "Battling with the Life Instinct"); and policy-focussed pieces recommending "Best Practice in Access to Maternity and Mental Health Services" (Fox). Such taxonomic endeavours would also be useful when it comes to identifying what does *not* appear in this series so far (some obvious examples include the experiences of people who do not speak English, or who were diagnosed in a forensic context). However, accepting that the portrait of schizophrenia produced by these narratives will be neither comprehensive nor representative, it seems more pressing to understand the continuities between these accounts within the context of *Schizophrenia Bulletin* than it does to advance yet another general typology of illness narrative (Hawkins; Hanninen and Koski-Jannes; Frank "Reclaiming an Orphan Genre") or to add to the fifty-two genres of life writing (Smith and Watson).

Genre is best thought of not as fixed or static lists of properties but rather as a dynamic structure of intelligibility, one that encompasses the paratextual elements already described. For literary and cultural theorist John 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" (102). Genre constrains, structures and shapes meaning and value, it projects a particular kind of world, and, perhaps most importantly, it produces specific effects of truth and authority (73).

One of the key organising dimensions of genre in Frow's account 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 (75). *Schizophrenia Bulletin's* First Person Accounts are in this respect marked by structural asymmetry: authors who have suffered mental distress, whether their own or their family member's, are writing primarily for clinical readers, addressing them as professional experts with the power to make decisions about people whose experience it is presumed they do not personally share.⁵ If all first-person or 'confessional' writing makes claims, implicit and explicit, to tell the truth, here the readers' clinical and scholarly authority carries an additional and distinctive weight. Some authors negotiate this by drawing on the rhetorical structures of academic argument: addressing psychiatrists and mental health policy makers directly, using sub-headings to introduce successive issues, backing up key points with examples from their own experience, and citing relevant sources (see ("Why Having a Mental Illness Is Not Like Having Diabetes"; Bockes; Gray). But even where authors make no use of such conventions, the speaking position or narrative voice of the First Person Accounts establishes a very particular kind of credibility: that of "insight."

When it is used in clinical contexts, the concept of insight has five clearly related dimensions: "the patient's awareness of mental disorder, awareness of the social consequences of disorder, awareness of the need for treatment, awareness of symptoms and attribution of symptoms to disorder" (Mintz, Dobson and Romney, 75). In mainstream psychiatry, schizophrenia is strongly associated with a *lack* of insight, a failure to recognise that one is ill and in need of medical care that is regarded as itself symptomatic of the condition. Insight is an ambiguous, highly-charged and frequently contested concept (Amador and David) and there are many who worry that "insight" in practice means "possessing and accepting psychiatric knowledge" while displaying "unquestioning acceptance and trust in whatever treatment the doctor deems fit to administer" (Galasinski and Opalinski 1460). Possessing insight can require both a "giving up" and a "giving in to":

The goal of my treatment seems to be the eradication of my meanings and the acceptance of my society's. I am supposed to learn "insight." Medication is supposed to suppress my Deep Meaning and replace it with saneness. (Hawkes 1109)

Insight is something that authors of the First Person Accounts discuss, as in the passage just quoted, but at a deeper level it is also performed across all dimensions of this genre, establishing continuity not only between first and second-person reports, but between these accounts and the clinical and scientific research of *Schizophrenia Bulletin*.⁶ Schizophrenia can be associated with very real *changes* to people's experience of time, of space, of their own bodies and relations with other people, and

the representation of these experiences within these narratives seems carefully controlled. The temporality of the First Person Accounts establishes a narrative present separated, if not quarantined, from the distressing, unstable, "symptomatic" past; the enunciative position emphasises clarity and consistency of communication; the projected world is one recognisable to anyone familiar with late twentieth- and early twenty-first century mental health services. The only First Person Account to depart from these conventions testifies to the consistency of their operation. "I have also with my own eyes seen at least 7 or 8 women who look [sic] me (my clones)," K Pushpa writes, and "that has reinforced my belief that the injections split me":

The coma injections or tablet-equivalent of them are given to make the patient comatose or – this is a guess! – to make a patient disappear! Maybe the patient disappears into another space-time dimension, and many events occur after which he/she appears back on the psychiatric couch or bed and opens his/her eyes without remembering anything of what had happened in the intervening period. Or perhaps – this is yet another guess – psychiatrists and neurosurgeons do things to the brain and body of the "patient." Sometimes secret brain transplants (partial or whole transplants) may be done – the lobe/s or certain parts of the brain may perhaps be exchanged with the brain parts of other persons! (3)

It seems highly probable that the author of this First Person Account, who appears to be the only writer in this series resident in the Global South, would be viewed by clinical readers as lacking insight and still in the 'grip' of delusional thinking. "Schizophrenia – A Victim's Perspective" points to the absence of "mad writing" from the series as a whole; the absence of particular kinds of claims (regarding experiences of cloning, for example) but also the absence of playfulness, irony, fantasy, figurative language, the appearance of other narrative voices, non-linear structures, and visual or typographic innovation. It would seem that fundamental to the 'genre of insight' is the exclusion of *anything*, even the fictional or fanciful, which might be perceived as in any way symptomatic of schizophrenia.

Recovering from, understanding and coping with schizophrenia are the most prominent themes in these accounts, where, as with most forms of illness narrative, the emphasis is on overcoming adversity. I have no wish to question the importance of this kind of storytelling but simply want to call attention to its specificity, to show that here, as elsewhere, there is nothing natural or self-evident about its operation. Indeed, narratives published in *Schizophrenia Bulletin* are not simply and spontaneously produced *for* the clinical professionals who are the journal's primary audience, but produced in collaboration *with* them. Many authors give explicit acknowledgement to the psychiatrists who have helped support the pieces to publication ("Taking the First Step"), and in an article which also, somewhat curiously, appeared in the space usually assigned to First Person accounts, Rudnick and colleagues provide a step-by-step guide for professionals seeking to help facilitate this. The collaboration between a 'content' expert (the person with schizophrenia) and a 'process' expert (the person with experience in the publication of scholarly work) they suggest has five steps: establishing a relationship; clarifying the themes and structure; writing, revision and submission. Rudnick and colleagues describe writing as "a creative act" (Rudnick et al. 2) about which it is difficult to give concrete guidance, yet the process they describe – while aimed at empowering the person who suffers "mental health

challenges" – is certainly not open to experiences, modes or methods which fall outside the model of academic co-authorship upon which it is based.

Narratives of schizophrenia have been marginalised, dismissed, and otherwise ignored by certain powerful sections of the psychiatric establishment. "What is at stake" in this conflict, as Estroff (283) observes, "is authority and authenticity concerning identity, definition, meaning, and experience in schizophrenia – and ultimately what happens to and about people with schizophrenia." The final part of this article is an exploration of the dynamics of this conflict beginning with a detailed discussion of one First Person Account which brings these issues to the fore.

III. Grand Rounds

Marcia Murphy's "Grand Rounds" opens with the description of her careful preparation for an intensive public performance: her presentation as a case in the grand rounds of her local teaching hospital:

I typed up what I might say and sent it to [my psychiatrist]. Dr. G said it was fine, but I worked on it some more. I changed and lengthened it considerably. I also practiced reading it out loud, speaking into a mini-cassette recorder. Playing it back, I could hear what parts needed work.

I wondered how the Rounds would go. My audience would be mainly psychiatrists, psychiatric residents, and medical students who viewed mental illness from the disease (biological) model. 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? (Murphy 657)

When the day finally arrives, Marcia is ushered onto the stage of a 200-seat lecture theatre. The interviewing psychiatrist, Dr Chapman, speaks in the language of clinical authority: "Describe the symptoms that you had in the early stages of your illness and how they affected you."; "Give your recovery story." The performance of Marcia's well-rehearsed narrative begins:

When I was in my teens, I was very depressed. I cut my wrists, and then, on one occasion, I overdosed on a bottle of aspirin. I believe this was a reaction to the emotional and physical violence in my home. Needing to get away, after high school I joined a religious cult, which operated under the pretence of being Christian but, in reality, was not. At one point, while in my early twenties and staying in New York City, I became psychotic. (658)

A brief period of hospitalization and sixteen years of suffering culminated in:

"a near-fatal suicide attempt in 1993. I then began to realise 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." (659)

Marcia is thanked for her participation and escorted from the lecture theatre. The Grand Rounds continue in the form of a closed debate amongst professionals as to the role of religious faith in recovery from psychosis. Using printouts of the formal presentation, and verbal reports from the participants, Marcia's First Person Account includes a record of this discussion:

"Marcia is not cured. I'm not sure I understand what you mean by your concept of 'recovery' [one resident objects].

"In psychiatric terms, we are generally taught that recovery means cure, but that is not the concept that people in the 'recovery movement' have," Dr. G said. "These people are 'life-oriented.' They see recovery as finding meaning and purpose in life. Instead of focusing on schizophrenia, the disease, they emphasise the potential for growth in the individual. [. . .] As providers, we need to listen to the stories of people with mental illness. Because of their lived experiences, they lend unique insight into mental illness and what makes recovery possible." (660)

Marcia Murphy's "Grand Rounds" functions as a 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 dramatises 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 to perform the role of '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 both 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 grand rounds is both an occasion and a set of conditions for a very specific kind of storytelling. Here, 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, will ideally be presented in a manner which minimises any manifestation of distress. The patient is called to articulate 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 clinical experience and expectation. Although an increasingly large number of readers of *Schizophrenia Bulletin* will have little if any contact with the people

whose illness they are researching (Thaker), for those doing clinical work first-person accounts are seen to play an important role in enhancing communication skills (Armstrong).

IV. Testimony

The grand rounds thus provide a powerful framework through which to approach the First Person Accounts but it is by no means definitive. Most scholars and practitioners in the medical humanities would advocate instead a reading of these texts as illness narratives or '(auto)pathographies' in the manner advocated for by figures like Howard Brody, Thomas Couser, Arthur Frank, Ann Hunsaker Hawkins, and Rita Charon.⁷ In contrast to the formality and didacticism of the grand rounds, theorists like Arthur Frank are committed to a "pedagogy of suffering" premised on thinking with stories (Frank, *The Wounded Storyteller* 23,144-145). For Frank

The most immediate problem of those who tell stories of illness is to be heard, to find others who will answer their story's call for a relationship. [. . .] Storytellers do not call for their narratives to be analyzed; they call for other stories in which experiences are shared, commonalities discovered, and relationships built. (Frank, "The Standpoint of the Storyteller" 355)

It is difficult to judge the extent to which readers of *Schizophrenia Bulletin* recognise or respond to the call of the "wounded storyteller." The dynamics of testimony alluded to by Frank seem more likely to arise when First Person Accounts are taken up and circulated in contexts not structured around the hierarchies of the clinical encounter, such as peer support groups, as the generic features outlined above – particularly those which inscribe the accounts within a broader framework of academic publishing – function to promote a more dispassionate detachment. Is this idea of a "pedagogy of suffering" something which therefore requires more active championing?

For many researchers and clinicians engaged in the medical humanities the answer would surely be in the affirmative, that 'narrative competence' in clinical and other settings is not simply a question of attending to the content of a patient's story but bearing witness to their suffering (Charon; B. Lewis). However, this approach is not without its critics:

What we are invited to endorse [by Frank and others] is a celebration of some – but by no means all – narratives. These are stripped of social context and social consequences. They are understood in terms of an individualised view of the self. Narratives are the means whereby the narrating subject, autonomous and independent of the medical profession, can achieve authenticity. Narratives are the means whereby illness may be transcended and turned into an apotheosis through self-mythologizing. This represents an almost total failure to use narrative to achieve serious social analysis. (Atkinson, "Narrative Turn or Blind Alley?" 339)

Atkinson's appeal is to shift the focus of analysis from a humanist and empathic engagement with the affective dynamics of the individual's story to one which locates and uses these narratives within a wider social context. Such a call might resonate strongly with the many writers in *Schizophrenia Bulletin* whose narratives present schizophrenia not simply in terms of specific symptoms or complaints, but as

inextricable from experiences of hospitalization, poverty, homelessness, stigma and discrimination (Hummingbird; MacPherson). At the same time, the stance advocated by Atkinson is potentially in tension with accounts, such as Marcia Murphy's, which seek recognition from their readers of the courage, resilience and fortitude shown in surmounting these experiences.

Although it may seem radical in the context of mainstream medical humanities research, Atkinson's approach to illness narratives neither interrogates nor ventures beyond the clinical framework of patients and illness. For this, we must turn to a fourth way of reading *Schizophrenia Bulletin's* First Person Accounts advocated by activists and scholars in the psychiatric survivor movement. Peter Campbell, founder of the UK group Survivors Speak Out, explains that the term "survivor" was taken up in a mental health context "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" (117). So, what would it mean to approach *Schizophrenia Bulletin's* First Person Accounts not as a collection of illness narratives written by patients, consumers and users of mental health services, but as the testimony of people who identify as survivors of distress, trauma and inadequate or inhumane psychiatric care?

"'Survivor' knowledge," as Mark Creswell has shown, 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" (1669). What distinguishes this approach from those already discussed is the emphasis on testimony. Drawing on the seminal work of Shoshana Felman, Dori Laub and Cathy Caruth, Creswell argues that:

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. (1671-2)

To read *Schizophrenia Bulletin's* 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.⁸ In the mode of the grand rounds we are called upon to learn from and about the patient; in Frank's model, to experience an empathic communion with the wounded storyteller; following Atkinson, to inquire into the social, economic and institutional forces which shaped the illness experience. Here, in recognising that we are witnesses to testimony, we are challenged to respond directly to the claim that psychiatry itself can be the cause of suffering and injustice; more profoundly, we are required through this engagement to reflect upon and take responsibility for our own 'position' with respect to the conceptualisation, categorisation, and treatment of mental distress.. Lucy Costa and colleagues have argued that mental health professionals have a tendency "to absorb resistance accounts, sanitise them, and carry them forward in ways that are useful for them,

without disrupting their dominant practices" (Costa et al. 87). The recovery narratives which are produced and consumed in certain clinical and advocacy settings tend to be highly formulaic stories of an individual's journey through and triumph over particular difficulties. Testimony, by contrast, is less reliant on linear or normative models of health. Crucially, as Costa and colleagues suggest, to be open to the dynamics of testimony is to start to recognise one's own position within the matrix of power-relations in which conflicts over the nature and meaning of mental ill-health, suffering and trauma are articulated. Reading first-person accounts of schizophrenia as testimony also allows space for the collision and coexistence of multiple ways of understanding unusual experience, including those which celebrate mad pride and mad culture (Curtis et al.).

The authors of *Schizophrenia Bulletin's* First Person Accounts are writing at a time when the public appetite for so-called 'misery memoirs' is matched if not exceeded by intense interdisciplinary interest in the study of narratives of illness and the practice of narrative medicine and narrative psychiatry. It is also a time marked by unprecedented opportunities for sharing first-person accounts of schizophrenia and mental distress with audiences across the world. While there is growing recognition that doing so can have personal, therapeutic, pedagogic, political and social value, activists and academics are also urging psychiatric survivors to 'recover' their stories and halt their circulation as 'patient porn' within a mental health system that recognises lived experience only as fits within biomedical or a neo-liberal recovery agendas (Costa et al.). It has not been my intention here to sanction a particular way of reading *Schizophrenia Bulletin's* First Person Accounts, or to downplay their diversity and the variety of contexts in which they will be encountered and purposes they might serve. What I have sought to do is to start to explore how these texts function as texts published within the specific context of a scientific journal, and how a 'genre of insight' serves to make them intelligible in ways that foreclose certain perspectives and modes of representation. This focus on textuality is a reminder to those in the medical humanities that first-person accounts are not a mechanism for providing 'untrammelled' or 'direct' access to people's experience; conversely, my discussion of the kinds of stances academic readers might adopt towards these accounts has endeavoured to tease out some of the attendant ethico-political commitments of such positions. In short, my appeal is for a more critical medical humanities; for more nuanced interdisciplinary approaches to the analysis of illness narrative; and for literary scholars to pursue more mutually illuminating dialogue with experts by experience as well as by clinical and academic profession. What remains now is the larger and more complex task of looking carefully, responsibly and comprehensively at what it is the authors of these First Person Accounts have to say about lives lived with schizophrenia.

Notes

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1. In my previous work (especially *The Sublime Object of Psychiatry*) I have discussed at length the controversies surrounding schizophrenia and its validity as a diagnostic category. These debates have been well-rehearsed (see Boyle; Bentall) including in the First Person Accounts which are the focus of this paper. Aware that the ongoing use of the term 'schizophrenia' risks continuing, to quote the Campaign to Abolish the Schizophrenia Label, "to perpetuate the myth that when talking about 'schizophrenia' we are discussing something that actually exists" (COPE Initiative) I have chosen not to abandon it on the grounds that the narratives I am examining here come into being as an archive precisely through their shared status within Schizophrenia Bulletin as first- or second-person accounts of something called 'schizophrenia.'

2. Gallagher writes: "Normal generation of narrative self depends on the proper functioning of a variety of cognitive capacities, including capacities for short-term temporal processing (working memory), self-awareness, episodic memory and reflective metacognition. Neuropsychological research suggests that in schizophrenia the mechanisms responsible for each of these elements are frequently disrupted. It should not be surprising that, as a result, schizophrenic narratives, and the self that is constituted through them, are problematic, both in structure and content" (336).

3. 64% women, 30% men, with gender undetermined in the remaining 6%.

4. The editorial policy on the journal web site simply states that "The Bulletin will publish first person accounts" but does not define these nor indicate the selection criteria used ("About the Journal"). In a personal communication, Professor Guntant Thaker clarified that unsolicited manuscripts were reviewed by the editor, and only "in rare instances sent out for reviews" (Thaker).

5. This asymmetry is further reinforced by the lack of open access to Schizophrenia Bulletin articles; for the first twelve months following publication, First Person Accounts are available only to those with expensive institutional or personal subscriptions.

6. However, judging from the relatively low number of citations of First Person Accounts in other contributions to Schizophrenia Bulletin, this rhetorical continuity functions to conceal rather than to bridge the epistemic gulf between these different forms of evidence.

7. This body of scholarship has focussed almost exclusively on somatic illness (but see Kleinman) and in many cases privileges the extended life narratives in published autobiographies; formally, in the context of their publication and at the level of content, the First Person Accounts could therefore constitute a hermeneutic challenge for scholars in this field.

8. In his more recent work with Helen Spandler on the psychiatric survivor movement, Creswell has posited a distinction between the "'academic intellectual' of social movements," and the "'organic intellectual' [who] becomes the 'activist' located *within* social movements," producing "knowledge *for* and *within* the social movement, not *about* it and *of* it." In doing this, they argue, the 'organic intellectual' confronts the imperative questions: "*Which side are you on?* and *What is to be done?*" (4, 5).

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