

Institution: Durham University
Unit of Assessment: English Language and Literature
Title of case study: New Approaches to Psychosis: Literary Thinking in Clinical and Cultural Contexts (CS3)
<p>1. Summary of the impact</p> <p>Research that uses methodologies from literary and cultural studies has enhanced the understanding of psychosis among psychiatric practitioners and the wider public. It has assisted the development of training and practice for clinicians, principally staff working in Psychosis Services in the UK and the USA, by developing their understanding of the value of literary theory and literary thinking for clinical work with psychosis. In addition, it has supported local, national and international psychosis support groups in offering assistance to voice-hearers and their families through greater understanding of cultural factors in psychosis and patient narratives.</p>
<p>2. Underpinning research</p> <p>The underpinning research was carried out principally by Dr Angela Woods in collaboration with Professor Patricia Waugh. Woods joined Durham's Centre for Medical Humanities (CMH) in January 2010; she is also a Research Associate in the Department of English Studies (with which she is submitted to REF2). Waugh has been a member of the Department of English Studies since 1989, and has brought her expertise in literary theory to medical humanities projects since 2000. Woods and Waugh have used their backgrounds in literary and cultural theory to develop new interdisciplinary methodologies that promote reciprocal exchange and 'entanglement' between the clinical, scientific and humanities disciplines. Together, their research finds a new role for literary and cultural theory not simply in challenging clinical and scientific accounts of human experience but in shaping a novel approach to the way that psychosis is conceptualised, researched and framed within clinical and cultural contexts. This is what they term 'literary thinking'.</p> <p>From 2004, Waugh has worked on how modern literature understands forms of psychosis (e.g. Waugh 2010). In 2009, Waugh led a collaborative research project at Durham on 'Thinking with Feeling', showing how literary thinking could contribute to psychologists', philosophers' and clinical psychiatrists' understandings of mind. Her work has promoted a discourse of bio-cultural complexity which challenges the vitalist/mechanist account of mind and life that underpinned the medical materialist debates of the early twentieth century. Her recent work (e.g. Waugh 2012) explores how literary and critical cultures intersected with such debates and shows how they helped to forge a 'phenomenological modernism' that engaged self-reflexively with issues at the heart of early phenomenological psychiatry, i.e. issues of dissociation, trauma and the rise of taxonomies of psychosis. Waugh's research informs a neo-phenomenological paradigm in literary as well as medical cultures. It shows the importance of literature in keeping open interpretative frames that were often closed down by assumptions of scientific irreversibility in the epistemological trajectories of biomedicine. As current psychiatry enters a new era of debate around its diagnostic or 'syndromic' categorisation, Waugh argues that modern literature can play a vital role in reconfiguring discourses and experiences of dissociation which have emerged as key features in the phenomenon of hearing voices.</p> <p>Research by Woods (2011) has taken up Waugh's insights and extended them to analyses of representations of schizophrenia in biological and phenomenological psychiatry, psychoanalysis, critical psychology, and postmodern and cultural theory. Its aim is to explore the relationship between clinical and cultural spheres, both to show the influence of culture in shaping and contesting psychiatric and psychoanalytic accounts of schizophrenia, and to understand how this clinical concept has been used by cultural theorists to explain experiences of the modern and postmodern. Woods (2013) has extended this research. Drawing on literary-theoretical studies of life-writing and genre, she has argued for a shift in the way that first-person accounts of psychosis are approached within a range of research and practice-based contexts. In clinical settings it is often supposed that written narratives provide 'direct access' to people's lived experience; in contrast, Woods has urged a recognition of the generic, philosophical, political and practical constraints that shape what can and cannot be said in these forms of testimony.</p> <p>The 'literary thinking' approach thus develops from Waugh's analysis of the shift to neo-</p>

Impact case study (REF3b)

phenomenology in literary and medical cultures, and is exemplified by Woods's studies of schizophrenia. Their approach underpins a large-scale collaborative project, 'Hearing the Voice' (HtV), begun in 2012, for which Woods, Waugh and 11 colleagues from Durham and elsewhere received a £1m Wellcome Trust Strategic Award. Woods is Co-Director of the project. It studies an experience strongly but not exclusively associated with psychosis: voice-hearing, or auditory verbal hallucinations. Rather than take notions of 'symptom' or diagnostic category as the starting-point, the project's focus on experience draws phenomenological, hermeneutic and cognitive neuroscientific perspectives into dialogue with the perspectives of clinicians, activists and voice-hearers. HtV embodies what Woods and Waugh have developed in their research, namely, the application of new approaches to 'psychotic' experience based on complexity, interdisciplinary 'entanglement', and an appreciation of the mutual influence of clinical and cultural spheres.

3. References to the research

1. A. Woods (2011). *The Sublime Object of Psychiatry: Schizophrenia in Clinical and Cultural Theory*. Oxford University Press.
2. A. Woods (2011). 'The limits of narrative: provocations for the medical humanities'. *Medical Humanities* 37.2: 73-78. doi:10.1136/medhum-2011-010045.
3. A. Woods (2013). 'Rethinking 'patient testimony' in the medical humanities: the case of *Schizophrenia Bulletin's* first person accounts'. *Journal of Literature and Science* 6.1: 38-54.
4. A. Woods (2013). 'The voice-hearer'. *Journal of Mental Health* 22.3: 263-270. doi:10.3109/09638237.2013.799267
5. P. Waugh (2010). 'Muriel Spark and the metaphysics of modernity: art, secularization and psychosis'. In *Muriel Spark: Twenty-First-Century Perspectives*. Ed. David Herman. University of John Hopkins Press. 63-93.
6. P. Waugh (2012). 'Thinking in literature: modernism and contemporary neuroscience'. In *The Legacies of Modernism: Historicising Postwar and Contemporary Fiction*. Ed. David James. Cambridge University Press. 73-95.

Markers of quality: Publication by high-quality peer-reviewed journals and academic presses. Waugh and Woods are co-investigators on 'Hearing the Voice', Wellcome Trust Strategic Award, £1m (2012-2015). Woods was awarded a Wellcome Trust small grant (£4,366) to run 'Hearing the Voice, an International Interdisciplinary Workshop' in 2011.

4. Details of the impact

Psychosis – its meaning, clinical conceptualisation and management, and representation within the wider culture – is a matter of concern to providers and users of mental health services, psychosis activists, and the wider public (it is estimated that 4 to 10% of the world population experience voice-hearing [see 5.1]). The underpinning research has applied literary and cultural approaches to psychosis in each of these domains, resulting in original ways to tackle an issue of fundamental significance. Dissemination of the research has been organised both to reach a wide public and specifically in order to instigate collaborations between academics, clinicians, carers and patients. The dissemination of the research has enabled distinct groups to influence one another. The application of the research has thereby gained greater reach and public significance. These processes have resulted in the provision of dedicated fora in which topics susceptible to stigmatisation have been – and continue to be – addressed openly and supportively.

Waugh has given numerous public talks on cognitive science and literary thinking, including the Inaugural Penguin Books Muriel Spark lecture on 'Spark, madness and metaphysics' (Edinburgh, 2008, to an audience of 200), and the opening keynote lecture to mark the 50th anniversary of the 'Two Cultures' debate in 2009, held at the Tate Modern and Science Museum to an audience of 450 that included scientists, science writers, journalists, artists and musicians. Woods launched the 'Schizophrenia 100 Years' public discussion series for the Newcastle Philosophical Society (NPS) in February 2011. Because she had 'really connected' with the 70 audience members who had personal or familial experience of schizophrenia, she was invited back, with Waugh, to speak on 'Pathologies of the Postmodern' in March 2013 (40 participants, with podcasts for Woods and Waugh). The NPS has specified that many of the service users in their audience had 'become more involved with the NPS in light of the earlier season on schizophrenia' [5.2]. Woods has engaged grass-roots activists in the global Hearing Voices Movement by presenting her research at the 2012 International Hearing Voices Congress in Cardiff

Impact case study (REF3b)

(300 participants) and the 2012 English Hearing Voices Network 25th Anniversary Conference in Birmingham (100 participants). She was an invited plenary speaker at Nottingham Contemporary's 'Antipsychiatry and its Legacies' event in February 2013 (100 participants; with live web broadcast and subsequent vodcast), and at Stanford University's 'Hearing Voices' symposium in April 2013 (120 participants, with live web broadcast & subsequent vodcast). Both Woods and Waugh gave talks and a workshop for 40 voice-hearers at Durham University in June 2013. Also in June 2013 Waugh drew on this research to debate theories of self at the Hay-on-Wye Festival (audience 150). These targeted dissemination activities have gone on to engage a wider, international audience through posts on the CMH blog which Woods edits (2,250 followers, named by the Online Education Database as 'One of the 50 Best Blogs for Humanities Scholars' in 2011) and through the 'Hearing the Voice' project blog (over 1,100 followers). Further events are planned for 2014.

These activities have (i) allowed psychosis to be discussed openly, beyond diagnostic contexts, and (ii) brought together patients, carers, health service professionals, psychosis support groups and academics from a range of disciplines. The key stage in the influence of this research occurred in November 2011, when Woods convened a voice-hearing workshop in Durham, at which she presented findings from her work; Waugh gave the keynote address on voice-hearing in twentieth-century literature. This workshop proved pivotal to developing partnerships with the major figures in voice-hearing research and activism, who are cited below. The following impacts resulted:

1. The underpinning research has fed directly into collaborations with practitioners in the Tees Esk and Wear Valley (TEWV) NHS Foundation Trust. In February 2012 Woods co-founded – with Charles Fernyhough (Psychology, Durham) and Nurse Consultant Valentina Short – the Joint Special Interest Group for Psychosis (JSIGP), a monthly forum for clinicians, academic researchers, service-users and family members to exchange ideas, research and best practice. Through the JSIGP forum, Woods and Waugh have both directly introduced clinicians to 'literary thinking', championing humanities-based approaches to psychosis, and have introduced greater rigour to the way in which patient narrative is understood. Taking up Woods's research on first-person patient testimony, the Trust-wide Psychosis Services Lead states that because mental health is 'intricately linked' to 'the narrative that we create around ourselves', this research has helped clinicians to 'make sense of our patients' narratives without resorting to a disease model'. [5.3] The key feature of Woods's and Waugh's collaborative work – its proposition of narrative complexity against the biomedical use of diagnostic categorisation – therefore comes through directly in their impact on clinicians. The same NHS Trust Lead on Psychosis has further praised the structure of this group as 'revolutionary': 'it has brought together patients, non-patient voice-hearers and [clinical] staff in a way that was not possible before', thus 'reducing stigma'. [5.3] The Clinical Lead in Early Intervention in Psychosis for the TEWV Trust states that the project has led to 'improved practice of staff working with voice hearers', which is 'hugely beneficial to clinicians and service users alike.... As a result, service users have felt less stigmatised' and this research has 'definitely contributed to their recovery'. [5.4] In May 2013, an event specially directed at voice hearers and their carers was organised by Woods and featured an interactive talk by Waugh. Formal evaluation was inappropriate but informal feedback was overwhelmingly positive.

2. Through a series of training days with the TEWV Trust, the underpinning research has shaped practice, influenced attitudes of clinicians and assisted in the professional development of NHS psychosis intervention staff.

(i) On 14 March 2013, Woods led a session on 'Interdisciplinary approaches to voice-hearing' at a Continuing Professional Development day for 60 doctors organised by the Royal College of General Practitioners.

(ii) Woods gave a keynote presentation on 'Narrative and Psychosis' at a day-long 'Best Practice in Psychosis' conference on 19 March 2013 to 69 participants; 80% of TEWV psychosis services staff surveyed reported that they found the session 'useful'; one responded 'the session was very useful [and enabled me] to understand the different narratives on psychosis and I would certainly be influenced by it in my clinical practice'. Another clinician praised the course's focus on 'the pros and cons of narrative' as 'useful' for their work with bipolar patients. A third, for whom 'story-telling is already a part of my work with young people' was 'inspired to continue to help' patients to 'find meaning in their experience'. [5.5] At a follow-up day on 12 June 2013, Woods worked with theatre director Tess Denman-Cleaver to deliver a workshop on 'Narrative and Psychosis: The Dynamics

of Storytelling'. Participants' responses indicate how ideas from these sessions have been taken up in clinical work. Several TEWV staff stated that the emphasis on narrative perspectives had already influenced their practice. Others remarked that the sessions had suggested new 'techniques to elicit positive aspects of [a] story' and that they had re-considered how to ask questions in an assessment. [5.5]

(iii) In partnership with colleagues at Leeds and Sheffield universities, and collaborating with the Andrew Sims Centre (a leading UK provider of training events for mental health workers), Woods co-facilitated a training course on 'Clinical Practice and the Value of Narrative: Analysing the Value and Application of Narrative and Stories in Delivering Healthcare' (Leeds, 11 June 2013). This event was also a NHS Continuing Professional Development course. Responding to the statement 'This course is very important in enabling me to do my job more effectively', the 15 participating doctors scored the event at 4.3 out of 5 (on a scale of 1 to 5). [5.6]

The underpinning research has also affected the training of clinicians internationally. In February 2013 Woods delivered two intensive modules for a new Doctorate in Clinical Social Work at Rutgers University, New Jersey, a programme designed to develop advanced clinical practice skills in theory and practice for mid-career clinicians. The programme director states that, as a result of Woods's training, these clinicians have experienced 'a fundamental shift in thinking about auditory hallucinations'. Her 'new ways of seeing voice-hearing' have prompted these clinicians to 'rethink [their] clinical practice'. (Woods will return to Rutgers in 2014). [5.7]

3. Through collaborations with voice-hearing support groups the underpinning research has promoted non-biomedical understanding of psychosis locally, nationally and internationally. Waugh and Woods have worked with the Hearing the Voice Movement, whose founders spent a term in Durham and attended the November 2011 voice-hearing workshop. Their enthusiasm for the project led to collaboration with the Chair of the UK National Hearing Voices Network. The Hearing the Voice project facilitated the UK Network in training 27 people (a combination of voice-hearers and mental health professionals) to establish new Hearing Voices Groups in North East England. The training was recorded and broadcast globally on BBC World Service on 28 June 2013. The Chair of the National Hearing Voices Network reports that this work has been crucial in 'reducing stigma' and in reaching those who could use the service's 'innovative approaches'. [5.8]

International collaborations have helped reduce stigma attached to voice-hearing. Woods's research on first-person accounts has been praised by the founder of the Chicago Hearing Voices Group for the way that it shows how 'narratives both shape and are shaped by clinical and popular needs and expectations'. It has 'begun to chip away at boundaries and barriers' and so is proving of 'tremendous value' to 'grassroots activists'. [5.9] Speaking at the TED 2013 conference in California, the Co-ordinator of the International Research Committee of Intervoice ('The International Community for Hearing Voices') recommended the HtV website as 'one of the few' that could 'introduce an American audience to the narratives of survivor activism'. This address has subsequently been viewed over 350,000 times and attracted over 300 comments via the TED website. She states that the effect of the underpinning research is 'to empower voice hearers; promote holistic, innovatory clinical approaches; and to challenge discrimination and stigma'. [5.10]

The underpinning research has therefore made significant progress in influencing clinical approaches, showing how the cultural understanding of forms of psychosis can be enhanced through a perspective derived from literary thinking. In affecting voice-hearers and their support groups, NHS staff, and mid-career clinicians in the United States, it has brought disparate groups together and begun the significant process of changing clinical approaches and public attitudes.

5. Sources to corroborate the impact

5.1 Intervoice: <http://www.intervoiconline.org/about-voices/essential-facts>. **5.2** Testimony from Deputy Chair, Newcastle Philosophy Society. **5.3** Trust-wide Psychosis Services Lead, and consultant clinical psychologist, TEWV NHS Trust. **5.4** Clinical Lead, Early Intervention in Psychosis TEWV NHS Trust. **5.5** Feedback, 'Best Practice in Psychosis', 19 March and 12 June. **5.6** Formal evaluation by Andrew Sims Centre. **5.7** Programme Director, Doctorate in Clinical Social Work, Rutgers University. **5.8** Chair, National Hearing Voices Network. **5.9** Founder, Chicago Hearing Voices Group. **5.10** Co-ordinator, Intervoice International Research Committee. http://www.ted.com/talks/eleanor_longden_the_voices_in_my_head.html