

Introduction: historical contexts to communicating mental health

Wynter, Rebecca; Smith, Leonard

DOI:
[10.1136/medhum-2016-011082](https://doi.org/10.1136/medhum-2016-011082)

Document Version
Peer reviewed version

Citation for published version (Harvard):
Wynter, R & Smith, L 2017, 'Introduction: historical contexts to communicating mental health', *Medical Humanities*, vol. 43, no. 2, pp. 73-80. <https://doi.org/10.1136/medhum-2016-011082>

[Link to publication on Research at Birmingham portal](#)

Publisher Rights Statement:
Checked for eligibility: 23/08/2017

Copyright information - Published by the BMJ Publishing Group Limited

Wynter R, Smith L Introduction: historical contexts to communicating mental health *Medical Humanities* 2017;43:73-80.

DOI: 10.1136/medhum-2016-011082

<http://mh.bmj.com/content/43/2/73>

General rights

Unless a licence is specified above, all rights (including copyright and moral rights) in this document are retained by the authors and/or the copyright holders. The express permission of the copyright holder must be obtained for any use of this material other than for purposes permitted by law.

- Users may freely distribute the URL that is used to identify this publication.
- Users may download and/or print one copy of the publication from the University of Birmingham research portal for the purpose of private study or non-commercial research.
- User may use extracts from the document in line with the concept of 'fair dealing' under the Copyright, Designs and Patents Act 1988 (?)
- Users may not further distribute the material nor use it for the purposes of commercial gain.

Where a licence is displayed above, please note the terms and conditions of the licence govern your use of this document.

When citing, please reference the published version.

Take down policy

While the University of Birmingham exercises care and attention in making items available there are rare occasions when an item has been uploaded in error or has been deemed to be commercially or otherwise sensitive.

If you believe that this is the case for this document, please contact UBIRA@lists.bham.ac.uk providing details and we will remove access to the work immediately and investigate.

Introduction – Historical Contexts to Communicating Mental Health

Rebecca Wynter, History of Medicine Unit, Social Studies in Medicine (SSiM), Institute of Applied Health Research, College of Medical and Dental Sciences, University of Birmingham, Edgbaston, Birmingham, B15 2TT, UK. r.i.wynter@bham.ac.uk

Leonard Smith, History of Medicine Unit, Social Studies in Medicine (SSiM), Institute of Applied Health Research, College of Medical and Dental Sciences, University of Birmingham, Edgbaston, Birmingham, B15 2TT, UK. l.d.smith@bham.ac.uk

Keywords: history; cultural history; patient narratives; mental health care; psychiatry

Word count: 4,821

Abstract

Contemporary discussions around language, stigma and care in mental health, the messages these elements transmit, and the means through which they have been conveyed, have a long and deep lineage. Recognition and exploration of this lineage can inform how we communicate about mental health going forward, as reflected by the ten papers which make up this special issue. Our introduction provides some framework for the history of communicating mental health over the past 300 years. We will show that there have been diverse ways and means of describing, disseminating and discussing mental health, in relation both to therapeutic practices and between practitioners, patients and the public. Communicating about mental health, we argue, has been informed by the desire for positive change, as much as by developments in reporting, legislation, and technology. However, while the modes of communication have developed, the issues involved remain essentially the same: most practitioners have sought to understand and to innovate, though not always with positive results. Some lost sight of patients as people; patients have felt and have been ignored or silenced by doctors and carers. Money has always talked – without adequate investment, services and care have suffered, contributing to the stigma surrounding mental illness. While it is certainly ‘time to talk’ to improve experiences, it is also time to change the language which underpins cultural attitudes towards mental illness, time to listen to people with mental health issues, and, crucially, time to hear.

Recent legislative changes and policy shifts in health and social care have prompted a lively public debate in the UK. Those who have experienced mental distress – from comedian Ruby Wax, historian Barbara Taylor, and psychiatrist Linda Gask, to the Members of Parliament Charles Walker and Kevan Jones – have spoken out, prompting reflection on the use of terminology and descriptive language, and on how words and whispers, imagery, and even fancy dress,[1] shape the attitudes of individuals, institutions and governments. At grass-roots level too, from blogs and Twitter accounts, people – such as @Sectioned_ and

@schizoaffected – are challenging the status quo about how mental illness or distress is discussed, depicted and treated. The aim of this special issue of *Medical Humanities* is to help develop an interdisciplinary exploration of the diverse approaches that can influence communicating mental health. While centred on the UK experience, it is hoped that this collection will contribute to a wider and deeper reflection on the ways and means in which people express themselves within the fields of medicine and health elsewhere in the world – particularly as British cultural tropes were exported through past imperial invasions, expeditions, and exploitation. We also hope we can begin conversations about the interrelation between these different types of communication and professional practice, government policy and social understandings.

In this introduction we suggest that history infuses, influences and informs how we discuss and approach mental health and practice mental health care today. Our introduction serves as the back-drop to the other nine papers in this collection, which consider photography, literature and theatre, first-hand accounts of patients or service users, discussions of theory, stigma, and language, ways of being in and relating to the world, and the dissemination, application and impact of research. Each of these areas of communicating mental health has a distinct and sometimes complex history of its own, which mirror broader developments in thinking and practice.

While the number of significant scholarly publications about communications in mental health practice has grown since 2000, these have often been written for students and trainees, and frequently for those working in nursing, caring and allied professions.[2,3,4,5] Even a cursory glance at the printed works of the past three centuries suggests that the discussions and advice about communication have largely been concerned with what patients convey to the (senior) practitioner, rather than *vice versa*. Certainly – and with the firm caveat that headline statistics frequently obscure more than they reveal – written complaints about the mental health services are on the rise; so too are those concerning the attitudes of staff and their communication of information to patients.[6] Historically, such complaints have tended to be brushed aside by claims that they were ‘due to psychosis or delusional states’ – a belief which continues to compromise how people diagnosed with or experiencing mental distress are listened to and heard.[7]

The lack of societal understanding, so effectively called out in the UK by the ‘Time to Change’ campaign, is all the more surprising, given that for centuries so much attention has

been focused on reading in others what has in the past been termed ‘madness’, ‘lunacy’, and ‘insanity’. Behaviour has been scrutinised, and physical signs observed – gait, the shape of the skull, and dress and appearance.[8,9,10,11,12,13,14] Clues have been discerned in images, in artwork, and in letters and handwriting; the latter was in 1870 described by psychiatrist (‘mad-doctor’, alienist, or asylum medical superintendent in earlier parlance) G. McKenzie Bacon as the ‘most reliable evidence of the state of a patient’s mind’ and ‘a sort of involuntary photograph’ (Fig. 1).[15]

The subjects and patterns of written thought and of speech have been dissected, as much as have brains and bodies. In this sense, what is now termed schizophrenia has proved of particular interest throughout the past 125 years. For some, it is the key to unlocking the workings of the mind; as psychologist Debra Titone has argued, ‘schizophrenia points to the dynamic interplay of linguistic, cognitive, and neural capacities’ in conveying ideas.[16] Moreover, particularly following the work of psychiatrist Kenneth Z. Altshuler, a rich seam of exploration during the past four decades or so has focused on how people diagnosed with both schizophrenia and hearing impairment understand auditory hallucinations. More recently ‘illustrated statement cards’ have been used to interview people with a range of hearing impairments and sign-language skills. The research discovered those with inherent and acquired deafness ‘heard’, ‘read’, and understood voice hallucinations differently.[17] Here, then, scientific inquiry deployed artwork to consider a range of communications surrounding mental health.

First isolated as a discrete form of mental illness by the German psychiatrist Emil Kraepelin and termed ‘dementia praecox’, the condition was renamed ‘schizophrenia’ by his Swiss colleague Eugen Bleuler in 1911, in partial recognition that the word ‘dementia’ was misleading. The search for clarity of expression and diagnosis has dominated discussions about mental health since the eighteenth century, and resulted in public controversies about accuracy. Developing from the 1750s via one of Britain’s most noted disagreements regarding the nature of madness and its treatment (that of Drs John Monro and William Battie, of London’s Bethlem and St Luke’s Hospitals respectively),[18,19,20] the process of classification continued through J. C. Bucknill and D. H. Tuke’s 1858 *A Manual of Psychological Medicine*. [21] While the *Manual* was eventually surpassed by the work of Kraepelin,[22] it would nevertheless run through numerous editions, mirroring the American Psychological Association’s *Diagnostic and Statistical Manual*, which has

historically been charged with enumerating (or manufacturing) disorders, he 2013 fifth incarnation attracting a barrage of very public derision.[23,24]

These theoretical and medical treatises, and the thinking they prompted amongst practitioners, have been fossilised in the annual reports of asylums and hospitals and in case histories of the past 200 years or more. Yet, case notes also communicate the trends and pressures that formed the doctor-patient relationship, as well as representing conversations between them and their sometimes collaborative formation of diagnosis.[25,26] In this way, historian Roy Porter's clarion call to listen to the patient's voice has been heeded.[27] Even so, the wide range of experiences in conveying mental health has yet to be aired widely - in particular those who have found communication challenging through illiteracy or language, as well as neuropsychiatric conditions such as aphasia and autism. Nevertheless there have been many more ways in which mental health and the voice of 'the patient' have been communicated and amplified.

In scholar and divine Robert Burton's 1621 *Anatomy of Melancholy* (Fig. 2),[28] and Scots physician George Cheyne's 1733 *The English Malady*,[29] language and their own experiences of mental ill-health were intertwined with notions of conveying identity and applying medicine. In turn, these two figures represent the medical shift from seventeenth-century mystical treatment to eighteenth-century evidence-based mad-doctoring. Their works helped pave the way for men and women to write autopathographies (self-narratives of illness, or, to borrow physician-pharmacologist Jeffrey Aronson's phrase, 'patient tales'),[30] including those by former patients, from the eighteenth-century poet William Cowper's *Memoir* [31] to Susanna Kaysen's 1993 *Girl, Interrupted*,[32] and Nicola Paget's 1997 *Diamonds Behind My Eyes*. [33] The 'narrative turn' in medicine, pioneered by Brian Hurwitz and Rita Charon,[34,35] has pivoted in part upon similar modern confessionals, as well as on case notes or patient histories and on the recording of legal cases.

The now familiar exposure of the voice of patient protest has an unexpectedly long antecedence. The volatile theologian Alexander Cruden ('Alexander the Corrector') went into print to lambast those he considered responsible for improperly carrying him off to a London private madhouse in 1739 and again in 1754, depicting the houses' proprietors and staff alike as unscrupulous, violent ruffians.[36,37] Others followed suit, such as John Perceval (son of assassinated British Prime Minister, Spencer Perceval), who in 1838 published an anonymous account of what he regarded as his brutal confinement at what

was widely considered one of the most humane private asylums of its day.[38] In the mid-nineteenth century, articulate protest, often through the press, cohered into the first significant patient-based pressure group, the Alleged Lunatics' Friend Society (with which John Perceval was intimately involved),[39] the early precursor of organisations like People Not Psychiatry in the 1960s, the Mental Patients' Union in the 1970s, and Survivors Speak Out in the 1980s.[40] Most recently, Twitter hashtags – such as #MedicatedAndMighty in 2015 – are galvanising many into activism who previously may not have engaged with such movements.

Historically, the communication of ideas on mental health practice has been intrinsic to developments in provision. During the eighteenth and nineteenth centuries, official inquiries and reports highlighted the very worst aspects of care, influencing public opinion and providing the impetus for fundamental reforms. A 1763 parliamentary Select Committee report led to the 1774 Madhouses Act, which required local magistrates to monitor and licence private facilities in their area. The graphic revelations of the 1815 Select Committee on the State of Madhouses, as well as its examples of good practice, motivated the reform lobby for the next half century and beyond. However, as has so often happened, selective hearing was applied to the evidence about Bethlem patient James Norris, not only ensuring that he became a totem for psychiatry because of his overtly cruel treatment, but also that the real experiences of those who lived and worked with this man who had been dangerously violent were lost. So too was his identity: James was commemorated by caricaturist George Cruikshank, but his 'real' name appears to have been *William* Norris.

The first nation-wide investigation of British public and private asylums, and the resulting powerful report of 1844, directly spawned legislation enforcing implementation of the national system of large institutions that defined mental health care for more than a century.[41] In the twentieth century, major government inquiries and reports continued the tradition of exposing widespread bad practice whilst also promoting ideas and methods deemed progressive at the time. The practical result has been key legislation such as the 1913 Mental Deficiency Act, the 1930 Mental Treatment Act, and the Mental Health Acts of 1959, 1983, and 2007. However, the negative, even carceral, legacies of law and language are difficult to unpick.

The writings of pioneering or charismatic practitioners regarding particular achievements in their institutions, or methods originated and deployed, have periodically had profound

influence on perceptions of mental disorder and the direction of mental health care. Samuel Tuke's 1813 eloquent explanation of the humane and person-centred 'moral treatment' at The Retreat in York (Fig. 3) and the 1838 proclamation by Robert Gardiner Hill of the abolition of mechanical restraint at the Lincoln Lunatic Asylum are prime examples.[42,43] Beyond these, the work – and notably the public clinical demonstrations, or what may even be called 'performances', of hysteria[44,45] – of Jean-Martin Charcot at Salpêtrière Hospital, Paris, drew a number of young practitioners, including, in the 1880s, Sigmund Freud.[46] Freud's psychoanalysis has, perhaps more than anything else since the early 1900s, pervaded Western ideas about what communicating in mental health practice should look like. While dreams and hypnosis may have been largely abandoned, talking therapies remain as a central paradigm in mental health practice.

The twentieth century significantly witnessed the extended reach of talking treatments. The dynamics of inter-personal communication were fundamental to the rise of group psychotherapy and the therapeutic community, and again key practitioners – such as Wilfred Bion and Maxwell Jones – were at the forefront of disseminating experiences and ideas.[47,48] Such developments were in part a response to the progressively challenging conditions found in twentieth-century mental hospitals. Nevertheless, they were difficult to implement within large patient populations in what were increasingly chronically underfunded facilities, depicted as 'isolated', 'imperious', brooding and moribund Victorian asylums.[49] As much as the sites had kept connected through developing technology – postal service, roads, rail, gas, electricity, telegraph, and telephone – their original therapeutic settings had also fostered silence; the medical authorities, after all, decided who in these closed communities had access to communication and the outside world. 'Do not for a moment underestimate their powers of resistance to our assault', urged the (later infamous) Conservative minister Enoch Powell in 1961, on seeking the closure of the old mental hospitals.[49] Certainly, it was not only politicians that were assaulting the foundations of institutionalised mental healthcare. From within the psychiatric profession itself emerged the anti-psychiatry movement, articulated in the writings of psychiatrists R. D. Laing and Thomas S. Szasz.[50,51]

In the 1960s and 1970s, labelling theory came to the fore, positing that words and/or diagnoses ensured that people could never escape their assigned labels. Descriptors of mental disorder have always variously proved stigmatic, controversial and fluid. Legislation

informed the terminology and definition of what has been described as ‘madness’ and ‘insanity’ – developing from the terms ‘lunatic’ and ‘idiot’, through to the 1913 Mental Deficiency Act distinguishing and formalising the terms ‘feeble-minded’ and ‘imbecile’, for example, and beyond to recent years when such words have been systematically removed from the statute book – except, of course, for the archetypal and evocative phrase: ‘not guilty by reason of insanity’.

Yet in their time, and through the rich medical discourse of the past two or more centuries, terminology has proved the basis for building a panoply of conditions and diagnostic categories. The asylums, their patients and the corresponding ephemera of institutional living spawned utopian and dystopian literature, rooted in reality and in fiction. Nevertheless, the *mise-en-scene* of the asylum and the image conveyed by the rhetoric of ‘the bad old days’ continued to be employed to press for greater consideration of the patients’ voice and for the reform of mental healthcare; through from Dr W. A. F. Browne’s 1837 *What Asylums Were, Are and Ought to Be*,^[52] ex-patient and lunacy reformer Louisa Lowe’s 1883 *Bastilles of England* (Fig. 4),^[53] Montagu Lomax’s 1921 *Experiences of an Asylum Doctor*,^[54] and Paul Warr’s 1957 *Brother Lunatic*,^[55] to the 1990s ‘Mad Pride’ movement.^[40,56] The abuse at Winterbourne View and neglectful dementia care at Mid-Staffordshire Hospitals Trust are beginning to be considered as the ‘bad old days’.^[57] All those who have worked in healthcare over the last decade (and beyond) should recognise that this both serves to obscure good practice and acts as a useful device to draw a line, play politics, stop listening, hide responsibility and/or suggest change has happened. The past is never simple and nor is the present; rhetorical devices and decisions about who is worth hearing cloud our understanding. Listening should not be reliant on scandal or provocation, and its meaning should encompass paying attention to what people are actually saying, even if it does not conform to a narrative that ‘we’ or the authorities seek to create.

Drawing on a two-day Institute of Advanced Studies workshop held at the University of Birmingham by what is now the Social Studies in Medicine research cluster, and introduced by two of its organisers, this special issue of *Medical Humanities* encompasses a further nine specially-selected papers from contributors working within the survivor movement and in the fields of psychiatry, psychology, law, drama, history and social science. We hope that in bringing together historians with contemporary reformers, researchers, practitioners and

‘service users’ – this term itself sits awkwardly with some – that we might expand the discourse. By doing so, we aim to build on the campaigning work of voluntary organisations such as Mind, Rethink, Young Minds and United Response, and help to break down the negative patterns into which we have repeatedly fallen and give pause to considerations of how we communicate mental health and what we might change.

The Arts have been a rich source for the communication of mental health, some works even establishing cultural tropes that have proved hard to uproot. In particular, unlike many methods of communication, literature and drama have historically been means by which the voices of women have been clearly audible, frequently to their detriment. The notion of women as unstable and emotional has inadvertently been promoted through fiction and its critique. Sandra Gilbert and Susan Gubar’s 1979 volume of feminist literary criticism, *The Madwoman in the Attic* explored nineteenth-century female writers. Their title, drawn from Bertha Mason’s situation in Charlotte Brontë’s *Jane Eyre* (1847), referred to texts including Mary Elizabeth Braddon’s *Lady Audley’s Secret* (1862), Charlotte Perkins Gilman’s *The Yellow Wallpaper* (1892), and Sylvia Plath’s *The Bell Jar* (1963).[58] However, ‘the madwoman in the attic’ phrase has arguably become glib shorthand which both recognises female mental ill-health and provides a rationale to suppress or control women.

Literature and drama contain at least as many (if not more) male authors and portrayals of male madness. Allan Beveridge’s paper, ‘The Presentation of Madness in Modern Scottish Literature’ demonstrates the diversity of authorship and conveys clearly how the arts reflect and embed characteristics and cultural identity. Sweeping between James Hogg’s 1824 *The Private Memoirs and Confessions of a Justified Sinner* and Jo McFarlane’s 2014 *Skydiving for Beginners*, Beveridge presents key hallmarks of Scotland’s vernacular literature. Madness has offered a portal into other-worldly realities and a chance to explore the themes so favoured by Scottish writers – ‘the supernatural, the Gothic and the religious’. Scottish discourse has offered a feedback loop between literature and psychiatry, particularly through R. D. Laing. As well as the coping mechanism of the dark Scottish sense of humour, authors have used their ‘own experiences of mental turmoil’ to infuse their writing and through it, examined personal identity and national character.

Lady Macbeth in Englishman William Shakespeare’s ‘The Scottish Play’ encapsulates, perhaps reflects, many of these traits. She has offered the playwright and the audience – including psychiatrists, such as John Conolly (1794-1866)[59]– a way of exploring emotion,

insanity, and the implications that the actions and experiences of the self and others have on mental health. Lady Macbeth is not alone in the Shakespearean canon, or in theatre or performance as a whole. From plays like *The Madness of King George*,^[60] and TV dramas and adaptations such as *Poppy Shakespeare*,^[61] to literature/film crossovers such as *The Snake Pit* ^[62] and *One Flew Over the Cuckoo's Nest*^[63]– as well as music, from the seventeenth-century ‘mad song’ poem Tom o’ Bedlam^[64] to *4st 7lbs* by Manic Street Preachers^[65]– drama, monologues and characterisation have been seen as an exercise in empathy and understanding and a means to explore being human. What Persephone Sextou and Paul Patterson’s paper – ‘Trapped in the Labyrinth’: Exploring Mental Illness Through Applied Theatrical Performance’ – offers is why and how such methods might be employed at a more intimate and inclusive level to unpick the ‘fear, shame and stigma’ that surrounds social attitudes to mental illness. Sextou and Patterson offer their experiences of using the labyrinth as a staging technique to create a ‘safe space’ for the audience to reflect on their personal attitudes and assumptions. They argue that, in Devised Theatre settings, empathy and understanding might be taught not told through the experience and the journey into and out of the labyrinth, and outsiders might be re-imagined and re-cast as heroes.

Such immersive encounters are also reflected upon in Rob Ellis’s article, ‘Heritage and Stigma: Co-producing and Communicating the Histories of Mental Health and Learning Disability’. Ellis considers his experiences of being involved in academically-funded history projects with two local learning disability and mental health charities. Indeed, recent funding initiatives have been rooted in communities and academics co-designing and co-producing research, which would have tangible outcomes. In the cases in point the primary pathway was museum exhibitions, and the hope was that these histories would help break down stigma and also showcase the contribution of terminology and language to social attitudes. Even so, Ellis emphasises the pivotal importance of the *collaborative* research, and the challenges that arise through the process. The degree of success, of course, was not quantifiable by the number of citations in the period bounded by the current Research Excellence Framework. Many efforts in the Humanities have longer-term influence and are reliant on time-consuming and energy-intensive working with groups and communities beyond the University campus. These may not be recognised, or even allowed space, despite the political and managerial ‘impact agenda’.

Nevertheless, the ethics and politics of communicating mental health through display – in museums, on television, in art – are complex. The old adage that ‘a picture tells a thousand words’ is hard to deny: one only needs to consider the ramifications for residential care of the British television documentaries *Silent Minority* (ITV, 1981) and Panorama’s *Undercover Care: The Abuse Exposed* (BBC1, 2011), or Bill Baldini’s 1960s TV10 exposés of Philadelphia’s Pennhurst State School and Hospital. In this introduction we have rejected using historical images which have often been and are still selected for their drama or shock value because they are considered to communicate mental illness; we have offered here less sensationalist pictures, to suggest historical images may contribute to the ‘othering’ of people with mental health issues. We assert that they communicate deeply embedded cultural attitudes to mental distress. However, Katherine Rawling’s paper – ‘She Sits All Day in the Attitude Depicted in the Photo’: Photography and the Psychiatric Patient in the Late Nineteenth Century’ Imagery’ – raises questions about how we ‘listen to’ what is being communicated in inherited visual images of mental health. Although embedded aesthetically and culturally in the Western European art of Goya and Hogarth, of Fuseli’s *Mad Kate* (1806-07) and Robert-Fleury’s *Pinel, médecin en chef de la Salpêtrière, délivrant les aliénés de leurs chaînes* (1876), and also in medical illustration, Rawling argues that nineteenth-century photographs of patients experiencing mental distress can be read as distinct visual imagery. Through her interrogation of text- and case-books, she suggests that these images were both evidence of professional networks of exchange and instruments of clinical practice. She also emphasises that these photographs are both evidence of self-fashioning and the deliberate presentation of the self through employing popular and non-institutional posing, as well as demonstrations of patient resistance and self-assertion – rather than, as has often been the contention, people always cowed by medicine.

The enormous power of words has been highlighted particularly in the contributions of Beveridge and Sextou and Patterson. It is a theme that permeates the four articles that consider contemporary issues in the field of mental health. Barbara Norden, in ‘Talking Personality’, speaks from the past fifty years of personal experience as to how words can hurt and damage, as much as they might describe and explain. She explores the historical components of the diagnostic minefield of ‘personality disorder’, and how it exemplifies the way terminology intended to clarify can simultaneously confuse, obfuscate and stigmatise. Other related terms, like ‘psychopath’ and ‘sociopath’, have acquired even more negative

connotations, not least through the vehicle of dark 'psychological' crime fiction and television police dramas, whose numbers seem to proliferate by the month. The relatively recent concept of 'Borderline Personality Disorder'[66] is arguably the clearest example of how an attempt to develop a more nuanced and complex descriptor has effectively created an even larger number of people subjected to a stigmatic, hurtful label. And yet, as Norden carefully concedes, there are some positive benefits to the use of diagnostic and descriptive terms. The real problems arise from the too-easy deployment of words that have become inherently judgmental.

A more profound set of dilemmas and hazards attached themselves to the word 'schizophrenia' in the second half of the twentieth century. As a diagnosis it continues to occupy a central place in the categorisation of serious mental illness. Nevertheless, many mental health professionals and 'service users' alike have expressed varying degrees of dissatisfaction and unease with a word that obscures and stigmatises far more than it elucidates. Despite the periodic protests of mental health charities and pressure groups, media misrepresentations of schizophrenia and 'schizophrenics' have continued unabated. In his thoughtful and provocative essay 'A Crisis of Meaning: Can 'Schizophrenia' Survive in the 21st Century?', Jerry Tew considers the factors that have created this challenging situation and whether there might be viable diagnostic or linguistic alternatives. As he demonstrates, however, there is a good deal more at stake here than the mere use of language. Strong vested commercial and professional interests are bound together in upholding the biological approach to psychiatry. As Tew shows, those interests are incentivised to retain an established diagnostic term, where continuing biomedical research anticipates heroic breakthroughs and lucrative pharmaceutical products. The consequence appears to be the deliberate setting aside of the diverse evidence that questions the schizophrenia entity, whilst also minimising the deep concerns of people who feel marginalised and stigmatised by the label. However, there are great risks attached to changes of terminology. As the historical transitions from 'idiocy' to 'mental deficiency', and then through to 'mental subnormality', 'mental handicap' and (latterly) 'learning disabilities' also illustrate, stigma is highly communicable and, within a few years, a new descriptor can acquire similar negative implications for the recipient as its rejected predecessor.

Over recent years there has been an increasing tendency in the UK, particularly within service provision for adolescents and young adults, to replace the contested term

'schizophrenia' with the more generic 'psychosis'. This option has been adopted by Michael Larkin, Elizabeth Newton and Zoe Boden in their semi-hypothetical consideration, 'If Psychosis Were Cancer'. However, as they indicate, the change in diagnostic label has so far done little to reduce the stark differences in the nature, quality and appearance of in-patient services for young people diagnosed with psychosis, as compared to cancer. These disparities can be attributed, in some measure, to the differential ways in which the conditions and those who suffer from them have been represented to the wider public. The consistently poor resourcing of mental as compared to physical illnesses by governments is one consequence. There is, nevertheless, one aspect where there has been notable progress toward greater parity of provision. Young people's community mental health services, based on the 'Early Interventions in Psychosis' model, have in many localities attained a degree of excellence. Yet, as Larkin et al highlight, those very services are currently facing an existential threat. It is barely conceivable that proven successful services for young cancer sufferers would be placed in a similar state of jeopardy, or that the imperatives of an organisational change agenda would be privileged over therapeutic effectiveness. What does this communicate about whether and how we prioritise mental health?

Much of the pioneering work in developing 'Early Interventions in Psychosis' was carried out in Birmingham by Max Birchwood and his colleagues.[67] Action research by practitioners into the model's effectiveness and development has continued to be a notable feature. In achieving this it is essential to design and deploy the most contemporary means of public health campaigning and communicating with potentially vulnerable young people in ways that engage them. A successful practical approach is elucidated by Charlotte Connor and her colleagues in 'Listen and Learn: How Personal Narratives Can Inform and Guide the Youth Mental Health Research Process'. Having identified that successful outcomes can depend upon reducing the time period during which a young person's psychotic illness remains undiagnosed and untreated, the team concentrated on developing accessible means by which indications of distress could be identified and essential advice and guidance disseminated. The design of online resources and social media proved crucial to carrying out the programme. The ensuing evaluative research directly involved young people, their teachers and carers as participants. Its positive results served to demonstrate the

effectiveness of an evidence-based, participatory approach to tackling the debilitating effects of serious mental illness among young people.

The final contribution to this special issue is Peter Bartlett's 'Afterword: Texts, Identity, Law, Policy and Communicating Mental Health'. The paper is a provocative reflection, taking stock of the papers that make up the themed collection. Set against the backdrop of the United Nations Convention on the Rights of Persons with Disabilities (CPRD), implemented in 2008 and directing global culture towards a social model of disability, Bartlett argues powerfully that we need dramatically to rethink the way we approach 'mental disability'. Critical of the acceptance of the traditional medical model of disability, which informs most current conversations about and approaches to mental health, including the other articles in this special issue, Bartlett challenges all of us – editors, authors, and readers of *Medical Humanities*, as well as wider society – to dump our historical baggage, which has brought us nowhere. In fact, it has taken us worse than nowhere, having led us to over-ride consent, enforce compulsion and judge some people to be less equal than others. Indeed, the co-production envisaged in the UN Convention – whether that practice is understood as meaning the involvement of, in consultation with, or designed by 'service users', patients, or people 'with mental disabilities', or 'experiencing mental health issues' – relies on organisation and direction by professionals, particularly clinicians. But directing, particularly through the discourses surrounding health and welfare in the austerity agenda, means little when all noise merely hides the confusion of those with the power. Whereas we have argued in our Introduction that it is time to listen, and all of our contributors have explored different ways and means of communicating, Bartlett questions whether we are even at the point of deciding what we want to say about mental health.

References

- 1 'Asda and Tesco Withdraw Halloween Patient Outfits', 26 September 2013. Available at: <http://www.bbc.co.uk/news/uk-24278768> (accessed 20/10/15).
- 2 France J, Kramer S, eds. *Communication and Mental Illness: Theoretical and Practical Approaches*. London: Jessica Kingsley Publishers 2001.
- 3 Bonham P. *Communicating as a Mental Health Carer*. Cheltenham: Nelson Thomes Ltd 2004.
- 4 Kossolapow L, Scoble S, Waller D, eds. *European Arts Therapy: Different Approaches to a Unique Discipline Opening Regional Portals*. Arts – Therapies – Communication Vol. III 2005.
- 5 Morrissey J, Callaghan P. *Communication Skills for Mental Health Nurses*. Maidenhead: Open University Press 2011.

- 6 Health and Social Care Information Centre. Data on Written Complaints in the NHS, 2014-15. 26 August 2015. <http://www.hscic.gov.uk/catalogue/PUB18021/data-writ-comp-nhs-2014-2015-rep.pdf> (accessed 7 Sept 2015).
- 7 Reinartz J, Wynter R. Introduction: Towards a history of complaining about medicine. In: Reinartz J, Wynter R, eds. *Complaints, Controversies and Grievances in Medicine. Historical and social science perspectives*. London: Routledge 2014: 1-33, 10.
- 8 Wynter R. 'Good in all respects': appearance and dress at Staffordshire County Lunatic Asylum, 1818-1854. *History of Psychiatry* 2011; 22: 40-57.
- 9 Young, R. M. *Mind, Brain and Adaptation in the Nineteenth Century. Cerebral localization and its biological context from Gall to Ferrier*. Oxford: Oxford University Press, 1990; 1970. Available at <https://books.google.co.uk/books?id=lcu3jpXcPH4C&printsec=frontcover#v=onepage&q&f=false> (accessed 10 Oct 2015).
- 10 Cooter R. J. Phrenology and British Alienists, c.1825-1845. Part I: Converts to a Doctrine. *Medical History* 1976; 20, 1-21. Available at <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1081688/> (accessed 20 Oct 2015).
- 11 Cooter R. J. Phrenology and British Alienists, c.1825-1845. Part II: Doctrine and Practice. *Medical History* 1976; 20, 135-51. Available at <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1081733/> (accessed 10 Oct 2015).
- 12 Sanders Chief L. J. The Charcot foot: historical perspective 1827-2003. *Diabetes/Metabolism Research and Reviews* 2004; 20, S4-8.
- 13 Schiller, F. Staggering gait in medical history. *Annals of Neurology* 1995; 37, 127-35.
- 14 Puri B.K. *Pocket Essentials of Psychiatry*. Edinburgh, London and New York: Saunders Elsevier, Third Edition, 2008, chapter 2.
- 15 MacKenzie Bacon G. *The Writing of the Insane, with Illustrations*. London: John Churchill and Sons 1870: 9.
- 16 Titone D. Language, Communication and Schizophrenia. *Journal of Neurolinguistics* 2010; 23: 173-5, 174.
- 17 Atkinson J R, Gleeson K, Cromwell J, et al. Exploring the perceptual characteristics of voice-hallucinations in deaf people. *Cognitive Neuropsychiatry* 2007; 12: 339-61.
- 18 Battie W. *A Treatise on Madness*. London: J Whiston and B White 1758. Available at https://books.google.co.uk/books?id=F6JbAAAAQAAJ&printsec=frontcover&source=gbs_ge_summary_r&cad=0#v=onepage&q&f=false (accessed 10 Sept 2015).
- 19 Monro J. *Remarks on Dr Battie's Treatise on Madness*. London: John Clarke 1778. Available at https://books.google.co.uk/books?id=KYSLJlb6W8IC&pg=PA1&source=gbs_toc_r&cad=3#v=onepage&q&f=false (accessed 10 Sept 2015).
- 20 Andrews J, Scull A. *Undertaker of the Mind: John Monro and Mad-Doctoring in Eighteenth-Century England*. London: University of California Press 2001: 43-70.
- 21 Bucknill J C, Tuke D H. *A Manual of Psychological Medicine: Containing the History, Nosology, Description, Staistics, Diagnosis, Pathology, and Treatment of Insanity. With an Appendix of Cases*. Philadelphia: Blanchard and Lea 1858. Available at <https://archive.org/details/b21270843> (accessed 10 Sept 2015).
- 22 *Lehrbuch der Psychiatrie* (first published in German in 1883), translated into English as Kraepelin E. *Trans. Diefendorf A R. Clinical Psychiatry. A Text-Book for Students and Physicians*. New York: MacMillan 1902. Available at <https://archive.org/stream/clinicalpsychia02diefgoog#page/n6/mode/2up> (accessed 11 Sept 2015).
- 23 Adam D. Mental Health: On the spectrum. *Nature*. 24 Apr 2013. <http://www.nature.com/news/mental-health-on-the-spectrum-1.12842> (accessed 10 Sept 2015).
- 24 Lane C. DSM-5 Controversy Is Now Firmly Transatlantic. *Psychology Today*, 11 Feb 2012. <https://www.psychologytoday.com/blog/side-effects/201202/dsm-5-controversy-is-now-firmly-transatlantic> (accessed 10 Sept 2015).

- 25 Suzuki A. Framing Psychiatric Subjectivity: Doctor, Patient and Record-keeping at Bethlem in the Nineteenth Century. In: Melling M, Forsythe B, eds. *Insanity, Institutions and Society: A Social History of Madness in Comparative Perspective*. New York: Routledge 1999: 115-36.
- 26 Jacyna L S. The Psychasthenic Poet: Robert Nichols and His Neurologists. In: Jacyna L S, Casper S T, eds. *The Neurological Patient in History*. New York: University of Rochester Press 2012: 167-83.
- 27 Porter R. The Patient's View: Doing Medical History From Below. *Theory and Society* 1985; 14: 175-98.
- 28 Democritus Junior. *The Anatomy of Melancholy, What it Is, with All the Kinds, Causes, Symptoms, Prognosis, and Several Cures of it. A New Edition by Democritus Minor*. Philadelphia: E Claxton and Company 1883 edition. Available at <https://archive.org/details/anatomyofmelanch00burt> (accessed 11 Sept 2015).
- 29 Cheyne G. *The English Malady: or, A Treatise of Nervous Diseases of All Kinds, as Spleen, Vapours, Lowness of Spirits, Hypochondriacal, and Hysterical Distempers &c*. London: G Strahan 1733. Available at <https://archive.org/details/englishmaladyort00cheyuoft> (accessed 11 Sept 2015).
- 30 Aronson J K. Autopathography: the patient's tale. *British Medical Journal*. 2000; 321, 1599-1602. Available at <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1119270/> (accessed 11 Sept 2015).
- 31 Cowper W. *Memoir of the Early Life of William Cowper, Esq. Written By Himself. And Never Before Published*. London: R. Edwards, 1816.
- 32 Kaysen S. *Girl, Interrupted*. New York: Turtle Bay Books 1993.
- 33 Paget N., Swannell, G. *Diamonds Behind My Eyes*. London: Gollancz, 1997.
- 34 Charon R. The Narrative Road to Empathy, In: Spiro H, Curnen MGM, Peschel E et al eds. *Empathy and the Practice of Medicine: Beyond Pills and the Scalpel*. New Haven: Yale University Press 1993:147-59.
- 35 Greenhalgh T, Hurwitz B. *Narrative Based Medicine: Dialogue and Discourse in Clinical Practice*. London: BMJ Books 1998.
- 36 Cruden A. *The London-Citizen Exceedingly Injured: Or A British Inquisition Display'd*. London, 1739.
- 37 Cruden A. *The Adventures of Alexander the Corrector*. London, 1754.
- 38 Perceval J. *A Narrative of the Treatment Experienced by a Gentleman, During a State of Mental Derangement; Discussed to Explain the Causes and the Nature of Insanity, and to Expose the Injudicious Conduct Pursued Towards many Unfortunate Sufferers Under That Calamity*. London: Effingham Wilson 1840. Available at <https://archive.org/stream/anarrativetreat00percgoog#page/n5/mode/2up> (accessed 10 Sept 2015). First published anonymously in 1830.
- 39 Hervey N. Advocacy or Folly? The Alleged Lunatics' Friend Society, 1845-63, *Medical History* 1986; 30: 254-75.
- 40 Jackson C. Mad Pride and Prejudices. *Guardian*, 3 Sept 2008. Available at: <http://www.theguardian.com/society/2008/sep/03/mentalhealth> (accessed 25 Sept 2015).
- 41 Jones K. *A History of the Mental Health Services*. London: Routledge and Kegan Paul 1972.
- 42 Tuke S. *Description of the Retreat*. York: W. Alexander 1813.
- 43 Hill, R.G. *Total Abolition of Personal Restraint in the Treatment of the Insane: A Lecture on the Management of Lunatic Asylums and the Treatment of the Insane*. London: Simpkin, Marshall and Highley 1839.
- 44 Showalter E. *The Female Malady. Women, Madness and English Culture, 1830-1980*. London: Virago 1987, 148-50.
- 45 Marshall J. Nervous Dramaturgy: Pain, Performance and Excess in the Work of Dr JeanMartin Charcot, 1863-1893. *Art and Pain* 2003; 4
<http://www.doubledialogues.com/article/nervous-dramaturgy-pain-performance-and-excess-in-the-work-of-dr-jean-martin-charcot-1862-1893/> (accessed 11 May 2016).

- 46 Gelfand T. Sigmund-sur-Seine: Fathers and Brothers in Charcot's Paris. In Gelfand, T. and Kerr J. (eds), *Freud and the History of Psychoanalysis*. Hillsdale, N.J.: Analytic Press 1992, 29-58.
- 47 Bion W. *Experiences in Groups*. London: Tavistock, 1961.
- 48 Jones M. *Social Psychiatry: a Study of Therapeutic Communities*. London: Tavistock 1951.
- 49 Powell E. Water Tower Speech. 1961. Available at <http://studymore.org.uk/xpowell.htm> (accessed 19 Oct 2015).
- 50 Laing R. D. *The Divided Self: An Existential Study in Sanity and Madness*. London: Tavistock 1959.
- 51 Szasz T. S. *The Myth of Mental Illness: Foundations of a Theory of Personal Conduct*. New York: Harper & Row 1961.
- 52 Browne W A F. Scull A, Intro. and ed. *The Asylum as Utopia. W. A. F. Browne and the Mid-Nineteenth Century Consolidation of Psychiatry*. London: Routledge 1991. Original text available at <https://archive.org/details/whatasylumswerea02brow> (accessed 11 Sept 2015).
- ⁵³ Lowe L. *The Bastilles of England; or, The Lunacy Laws at Work*. London: Crookenden and Co. 1883. Available at: <https://archive.org/details/bastillesenglan00lowegooq> (accessed 11 Sept 2015).
- ⁵⁴ Lomax M. *The Experiences of an Asylum Doctor; With Suggestions for Asylum and Lunacy Law Reform*. London: George Allen and Unwin 1921.
- 55 Warr, P. *Brother Lunatic*. London: Spearman 1957.
- 56 Reaume, G. A History of Psychiatric Survivor Pride Day During the 1990s, *The Consumer/Survivor Information Resource Centre Bulletin* 2008; 373: 2-3. Available at http://www.csinfo.ca/bulletin/Bulletin_374.pdf (accessed 31/10/2015).
- 57 Donnelly, L. Mid Staffs campaigners: Don't trust Labour on the NHS. *Telegraph*. 10 Feb 2015. Available at <http://www.telegraph.co.uk/news/health/news/11404250/Mid-Staffs-campaigners-Dont-trust-Labour-on-the-NHS.html> (accessed 31 Oct 2015).
- 58 Gilbert S. M, Gubar S. *The Madwoman in the Attic: The Woman Writer and the Nineteenth-Century Literary Imagination*. New Haven and London: Yale University Press, 1979.
- 59 Conolly J. *A Study of Hamlet*. London: Edward Moxon & Co., 1863.
- ⁶⁰ Bennett A. *The Madness of King George*. London: Faber & Faber 1993.
- ⁶¹ Ross B, dir. *Poppy Shakespeare*. London: adaptation for Channel 4. First broadcast 31 Mar 2008.
- ⁶² Litvak A, dir. *The Snake Pit*. 20th Century Fox 1948.
- 63 Forman M, dir. *One Flew Over the Cuckoo's Nest*. United Artists 1975.
- 64 'Tom o'Bedlam'. In Bloom H. *How to Read and Why*. New York: Touchstone, 2001. 104-09.
- 65 Manic Street Preachers, '4st7lbs', *The Holy Bible*. Epic, 1994.
- 66 Lieb, K. et al, 'Borderline Personality Disorder'. *The Lancet* Vol. 364, 31 July 2004, 453-61.
- 67 Birchwood M., Fowler D., Jackson C. (eds). *Early Intervention in Psychosis: A Guide to Concepts, Evidence and Interventions*. Chichester: Wiley, 2000.