Developing a not-knowing approach to experiences conventionally described as severe mental illness

by

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Preface: my academic and professional journey to this point

Career

I qualified as a clinical psychologist at the University of London Institute of Psychiatry in 1992. At that time qualifying awards were at MSc rather than doctoral level. For most of the 1990s I worked full-time in the UK National Health Service, mainly in the multidisciplinary settings of acute psychiatric wards and community mental health teams. In 1997 I took up my first academic role, a part-time research tutor post on the Doctorate in Clinical Psychology at University College London, which I held alongside my clinical role. In my NHS role I took up my first Consultant post in 1998, overseeing adult psychology provision in one of an inner London NHS Trust's two boroughs.

In 1999 I moved to Canterbury Christ Church University College (as it then was), initially as a research tutor and more recently as a director of the Doctoral Programme in Clinical Psychology (D Clin Psy), a research degree. The main focus of my post is the development, organisation and delivery of this programme, but the role also includes research and research supervision. In the intervening years I have supervised approximately 35 - 40 doctoral dissertations, and examined a similar number. I have also acted as external examiner for doctoral theses at the universities of Leicester and East London.

Scholarly work

Recent years in particular have been productive ones for me academically and I now have over 80 publications and 800 citations, an h-index of 14 and an i-10 index of 17. These can be viewed on Google Scholar: https://scholar.google.com/citations?user=7rcheaAAAAAJ&hl=en or in the university's research repository: https://repository.canterbury.ac.uk/researcher/80v92/ms-anne-cooke.

My research interests lie at the intersection of clinical psychology and critical psychology. Specifically, I have an interest in the effects of the currently dominant disease model in mental health: the conceptualisation of psychological problems as 'illnesses like any other' with an assumed origin in brain dysfunction of some sort. My particular interest is in the experiences that attract diagnoses such as schizophrenia, psychosis or bipolar disorder, known collectively as ‘severe mental illnesses’ (SMI) (e.g. Department of Health, 2018).

How my interest in this topic arose

My interest in these questions arose primarily from my work in the NHS within acute mental health care. I had the privilege of working psychologically with many people whom the system saw as suffering from SMI. I was repeatedly struck by the way in which, in the context of psychological therapy, when there was time to listen in detail to people’s stories and to understand the events and circumstances of their lives and the way they had come to see the world, ‘symptoms’ which had appeared strange or arbitrary would often come to make more sense. The reasons that people had developed particular ‘symptoms’ (experiences, emotions or beliefs) were often complex, interacting, and incompletely specifiable. The more of these conversations I had with people, and the more I looked into the theoretical and empirical literature (see below), the more obvious it became that system’s assumption that ‘symptoms’ reflected specific, treatable brain dysfunction was just that, an assumption. It was not always a helpful one: whilst some people found it helpful to see themselves as ill, this was far from being the case for everyone. Nevertheless, the idea of SMI was the dominant idea guiding service delivery. It remains such, and indeed is codified in laws giving professionals the right to detain, and, if necessary, medicate by force, those seen as mentally ill. Many of the people I saw had been in contact with mental health services for years or even decades, but had rarely been offered the chance to talk about how they themselves understood their difficulties or about the (often traumatic) events and circumstances of their lives. Instead, most had been told that they had a chronic, deteriorating brain disorder and would need to take psychiatric drugs for the rest of their lives. This powerful narrative, in combination with NHS workers’ practical and emotional overwhelm, appeared to dictate what happened in services. Attempts to understand what might have brought someone to this point were often sidelined or eschewed in favour of containment and medication, by force if necessary. The latter often appeared to be seen as the core role of services, and in the context of overstretched resources it often seemed to become their only role, especially in the case of inpatient services. Whilst superficially it appeared to offer an attractive clarity of role for workers, it was also a narrative which brought its own stresses, casting them as needing to be ‘experts’ with answers, often reducing them to monitors of risk and enforcers of compliance with medication, leading to conflict with service users. As psychiatrists Bracken & Thomas

(2001) and Pariente (2018) have pointed out, psychiatry is the only branch of medicine whose patients often organise to fight it. Whilst there are no anti-oncology or anti-gynaecology movements, there is an active and vocal ‘antipsychiatry’ movement whose adherents often see themselves as ‘survivors of psychiatry’ (Arnold, 2018).

Engaging with critical realism and critiques of medical naturalism

In the early 1990s I encountered social constructionist, post-structuralist and critical realist scholarship on the topic of ‘mental illness’ (e.g. Anderson & Goolishian, 1992; Parker et al., 1995; White, 1987). This body of work situated the mental illness idea as one among a number of (competing or complementary, depending on one’s point of view) ways of viewing the phenomena in question. I was excited to find an intellectual frame for, and validation of my own observations and reflections as a clinician. Hitherto my training had been largely within a framework of scientific realism or ‘medical naturalism’ (Pilgrim & Bentall, 1999). Following Kraepelin, whom Eysenck (1979) describes as the founder of modern scientific psychiatry, this approach assumes that mental health problems are natural kinds, illnesses like any other (Malla, Joober & Garcia, 2015), and can be investigated in the same way. The assumption is that research is incrementally providing a more and more accurate description of reality, and is revealing, or will in future reveal, discrete brain or other pathologies underlying distressing experiences such as paranoia or voice hearing. The latter are typically assumed to be symptoms of an independently existing disease entity, in this case schizophrenia (Pilgrim & Bentall, 1999).

By contrast, social constructionism, following the philosophers Foucault (e.g. 2006) and Derrida (e.g. 1973) understands concepts such as mental illness or schizophrenia as culture-bound representations of an infinitely varied and ultimately unknowable human condition. The study of ‘psychopathology’ as an entity is replaced by a study of the ways in which particular experiences or behaviours come to be seen in this way, how they are represented (‘discourses’) and the actions to which particular representations give rise. Social constructionist critics of the mental health system (e.g. Boyle, 1990, 2000; Hallam, 2017) argue that absence of hard signs or ‘biomarkers’ in psychiatry renders problematic most of its ‘diagnoses’. The majority of psychiatric diagnoses are ‘functional’ i.e. defined in the absence of hard signs by comparing the experiences that the person describes, or aspects of their observed behaviour, to an agreed list of symptoms. Critics (e.g. Johnstone, 2014) argue that this means they are not really diagnoses in the usual sense of the word, i.e. explanations.

Rather they are just (re)descriptions of what the person is complaining of and fail to convey any new information.

A number of authors have argued that the word ‘diagnosis’ is therefore a misleading one in the mental health context because it implies that the labels have explanatory value whereas, in fact, they are just category labels. These authors (e.g. Johnstone, 2014; Kinderman, Read, Moncrieff & Bentall, 2012) also point out that the various category definitions are somewhat arbitrary in that ‘disorders’ are voted into and out of existence by committee, and change as social norms change. The classic example is the 1973 vote by the American Psychiatric Association, following extensive political lobbying, to remove the diagnosis of homosexuality from the second edition of its Diagnostic and Statistical Manual (DSM).

Engaging with the service user/survivor movement and the ‘grey’ literature

Around the same time (i.e. the mid-1990s) I first came across the service user/survivor movement. Many of those allied to the movement reject the idea that their problems are necessarily illnesses with their origin in the brain, pointing instead to the role of life events and circumstances such as oppression or abuse. Many were publishing reflections: this so-called ‘grey literature’ (i.e. published outside of mainstream academic outlets) was proliferating. Two accounts in particular had a big impact on me. The first was a slim volume entitled ‘Self-Harm: perspectives from personal experience’ (Pembroke, 1994).

One passage from the book, in which Louise Pembroke describes her experience and reflections, chimed strongly with my own observations and experiences of working in the system:

> *Psychiatry's range of descriptions of our distress is couched solely in negative terms... "Illness" equals unwanted, bad, abnormal. Something that should be eradicated or cured… Diagnostic labels…devalue and demean people fundamentally… [and stop] the individual from owning the experience and finding his/her own language and interpretation… Identity is defined by psychiatry's labels… I have come to the conclusion that people are not studied by psychiatry and psychology, merely categorised and described… In categorising the distress, the distress itself is not acknowledged… Psychiatric training disables the worker's ability to perceive.*
> Pembroke (1994), p.36

Another important conceptual resource was a 1994 special issue of the *Journal of Mind and Behavior* entitled *Challenging the Therapeutic State*. I found an article by Michael Susko, a social worker and former psychiatric patient, entitled *Caseness and narrative: contrasting approaches to people who are psychiatrically labelled*, particularly thought-provoking.

I recently read this paper again for the first time in many years, and realised how key it had been in alerting me to the effects of what Susko calls the 'caseness' approach (roughly equivalent to the 'SMI' approach) within services.

'*In brief, Caseness emphasizes making a diagnosis of illness and stopping its symptom expression. The Narrative approach, on the other hand, supports individuals coming to their own voice by allowing their story to unfold and to be told'* (Susko, 1994, pp.87 – 88).

I am struck again by how well this paper demonstrates the radically different ways in which the same experiences can be seen and understood. Susko contrasts clinical accounts of events with personal accounts by the people concerned:

> *'Joe Green tells of an incident at a state hospital:*
>
> > *"Due to my excessive spiritual reading and my disorientation I started to act out the things I had read. I would throw books on the floor and think I was waking up humanity ... An attendant ... wrestled me to the floor…put a needle in my backside."*
>
> *No one asked Joe why he was throwing books on the floor… having already established that he was "paranoid schizophrenic." ... The Caseness approach labels the unusual experience as a disease entity… separating the person from "normal" people. The Narrative approach, on the other hand, seeks to place the life story with its difficulties as part of a common human experience.*
> (Susko, 1994, p.88).

These two passages echoed and helped consolidate my own reflections working on an acute psychiatric ward. The same presenting problems could elicit very different responses depending on the lens through which they were viewed. Even within the medical frame people were treated differently depending on the diagnostic category to which they were assigned. To take hearing voices as an example, occasionally this experience might be seen as an understandable part of, say, bereavement. This tended to be where there was a very obvious psychosocial precipitant that was hard to ignore. More commonly it would be viewed as a symptom of psychosis and the person detained in hospital and medicated, against their will if necessary. The specific diagnostic category applied appeared to be influenced not only by the person's 'symptoms' but by wider characteristics such as their background, cultural similarity (and therefore intelligibility) to the categorising clinicians, and social stereotypes. For example, as we later came to describe in 'Understanding Psychosis' (Cooke, 2014; 2017a), young black men are more likely than others to receive a diagnosis of schizophrenia, even if the problems they are experiencing are similar. Social class also appeared to play a role, as reflected in a joke that former service user Ron Coleman used to tell (see James, 2002):

> *Q: What's the difference between a schizophrenic and a manic*-*depressive?*
> *A: The manic depressive is the one who owns a credit card.*

In some cases (particularly where the person was young and female, and presented with self-harm), the voices might be seen as 'pseudohallucinations' and the person as having a personality disorder. In this case they might be turned away even if in acute distress because they were seen as 'not really ill' and therefore not the responsibility of mental health services. They might even be blamed or seen as a 'time-waster'. In some cases, the service would yo-yo in its approach as it felt forced to respond to acute suicidality – usually with a very controlling approach – and then discharged the person with little or no follow-up care as soon as the acute risk appeared to have passed. Little seems to have changed in this regard over the intervening years, as evidenced for example by the recent controversy about the 'Serenity Integrated Monitoring' approach used in some NHS Trusts (see e.g. Pring, 2022).

Another reason that the narrative approach resonated with me was its recognition that painful experiences are not always only negative: even periods of what appears to be breakdown can also be transformative, leading to personal growth and valued outcomes. This idea contrasted with services' relentless focus on the negative, and in latter years has led to an interested in what might be called ‘transformative’ approaches to mental health crisis (e.g. Cooke & Brett, 2020).

Research and methodological interests

These experiences of working in psychiatric settings early in my career, together with the theoretical resources that helped me make sense of them, have influenced my research interests as well as my epistemological and methodological approach. In the contested arena of mental health, I am sceptical of the knowledge claims of (naïve, in my view) scientific realism. However, I stop short of radical social constructionism which, given its lack of clarity regarding ontological realism (Pilgrim, 2020a) I feel risks denying the importance of the very real events, circumstances and individual differences that can play a role in distress. Instead I adopt a critical realist approach (Danermark, Ekstrom & Jakobsen, 2001; Pilgrim, 2020a). This has informed my research methods which have mainly been qualitative, often either deconstructing professional and societal narratives (e.g. Cooke, 2008), or foregrounding those of the people directly affected (e.g. Jackson, Hayward & Cooke, 2011, Prytherch, Cooke & Marsh, 2020).

Publications

Having outlined the focus of my work and how my interest in the topic arose, I turn now to the publications themselves. First I characterise the work and list the publications I am presenting here, arranged into four themes which together address the question of the utility of the SMI concept and possible alternatives. I then outline some indications of quality and of impact, dividing the latter into impact on service users and their families; on clinicians; on education and training; on policy and policymakers, and finally on the media and public debate. The commentary itself then follows, outlining how the presented work has addressed the value of the SMI concept and explored alternatives.

Characterisation of the work

Some of my work has been theoretical but a significant proportion is empirical. In deciding which of my outputs constitute research I have drawn on the REF definition: ‘*A process of investigation leading to new insights, effectively shared… it includes… the invention and generation of ideas… where these lead to new or substantially improved insights’* (Research England, 2019).

The body of work I am presenting can be divided into four related and sometimes overlapping streams. The first examines **problems with concept of severe mental illness** (e.g. Allman, Cooke, Whitfield & McCartney, 2018; Cooke, 2008; Cooke & Brett, 2020; Cooke & Kinderman, 2018; Cooke, King & Greenwood, 2016; Kinderman, Allsopp & Cooke, 2017).

A second stream has examined possible **alternatives** to the severe mental illness concept and associated technologies (e.g. Cooke, 2014; 2017a; Cooke & Kinderman, 2018; Jackson, Hayward & Cooke, 2011; Jones, Lobban & Cooke, 2010).

A third stream has examined how these alternatives are **drawn on in professional practice**, including by clinical psychologists (e.g. Cooke & Brett, 2020; Court, Cooke & Scrivener, 2017; Cooke, Smythe & Anscombe, 2019).

A final stream examines how these critiques and alternatives can be **disseminated** within society and incorporated in professional training (e.g. Cooke, 2014; 2016a; 2017; Cooke, King & Greenwood, 2016

Indications of quality

The works I am presenting have all been published in peer-reviewed journals, or, in the case of books, either by mainstream academic publishers or by the British Psychological Society. They total over 100,000 words and have had significant impact, as outlined in a REF impact case study that the university asked me to prepare (Cooke, 2019).

Indications of Impact

For reasons of space, I will limit discussion of my work's impact to my most highly cited output, *Understanding Psychosis and Schizophrenia* (Cooke, 2014; 2017a). The paper's release led to extensive national and international media coverage including by BBC Radio 4's *Today Programme* and by the *New York Times*. It was cited by the United Nations (United Nations, 2017) as evidence of a paradigm shift in the field. In May 2017 I was presented with the British Psychological Society's *Practitioner of the Year* award in recognition of this and related work. I now have a large social media following (over 20K followers on Twitter) and have been named as a 'mental health leader' by the 'Mental Elf' website and a 'renowned critical voice' by Sheppard (2022). I am frequently invited to provide training or deliver public lectures about psychosis, for example by the magazine New Scientist. In 2020 *Understanding Psychosis* was the first BPS public information document to be made available from booksellers. Three translations have been published (Japanese, Swedish, Spanish): others are in preparation. The charity 'Star Wards' collaborated with the BPS to develop an easy-read version aimed at young people (Cooke, 2020) and a video (BPS/Star Wards, 2021).

Impact on service users. Indicative quotes include:

'How different things would have been if this had been around when I was in hospital'. Dr Eleanor Longden, University of Manchester

'At any time over all these years I'd have done anything to have been given a handbook like this'. Nicky Hayward, service user and former carer.

'I've been working with a young girl… She told me that the most helpful thing was giving her your psychosis report to read…which had made her realise that having a psychotic episode does not mean that she will inevitably develop schizophrenia and become chronically mentally ill. This has [given her] *the confidence to go back to university.* Prof Fiona Lobban, Lancaster University

Impact on clinicians: Many clinicians have been in touch to say how the document has changed their practice. Some examples follow**:**

'Your paper on psychosis has fundamentally changed the way in which I view psychosis & given me enormous support for work with clients'. Olivia Streater, psychotherapist

'Reading 'Understanding Psychosis' when I was working on a locked ward persuaded me to train as a clinical psychologist' Dr Melanie Rendall, Homerton Hospital NHS Trust

'I would have been very proud if the Royal College had written this report.' Prof Sir Robin Murray, Royal College of Psychiatrists

Impact on Education and Training. 'Understanding Psychosis' now features on many course syllabi for mental health workers. The BPS has developed it into a training pack: a set of publicly available materials for a one-day training event aimed at mental health staff (Solly & Currell, 2017). This has been used in NHS services around the UK. Some indicative quotes from educators follow:

> *'Understanding Psychosis' is the key text I use when providing training on psychosis to national and international audiences'*. Dr Alison Brabban, NHS England National Clinical Advisor for SMI

> *'Understanding Psychosis' is without doubt the most important and impactful piece of work in this area, influencing research, policy and practice, and transforming lives. We have trained thousands of professionals… 'Understanding Psychosis' is a lynchpin of that training. We have heard from countless individuals that it has been seminal in changing their practice…* [and] *it has been invaluable for people with lived experience and their families, helping them make sense of their experiences and providing hope'* Akiko Hart, Director, *Voice Collective* (national organisation for young people who hear voices)

Impact on policy and policymakers: As mentioned above *Understanding Psychosis* was cited by the United Nations in its report on 'The right of everyone to enjoy the highest standard of physical and mental health' (United Nations, 2017) in support of the assertion that '*the psychosocial model has emerged as an evidence-based response to the biomedical paradigm'*.

It has had a widespread impact on policy and commissioning. NHS England National Clinical Director for Mental Health, Dr Geraldine Strathdee, commissioned slides outlining the main messages for use in her briefings to service commissioners around the UK, exhorting them to ensure adequate provision of psychologically informed treatment. On retirement from the role she thanked me for *'the inspiration of your book on psychosis which has changed so many perceptions and developed humane attitudes'.*

Luciana Berger MP, Shadow Minister for Mental Health, and Dr Lisa Cameron MP both requested copies and have since drawn on it in speeches.
Indicative quotes from policy makers and politicians include:

'This important report will be a vital resource… The British Psychological Society are a great force for change right at the grass roots of frontline services.' Dr Geraldine Strathdee, NHS England National Clinical Director for Mental Health

'I welcome the authors' commitment to explaining, in clear terms, what lies behind people's experience of psychosis.' Luciana Berger MP, Shadow Minister for Mental Health

'I am delighted to add my voice in recommending this report, which … helps us to understand (psychotic) experiences better and to empathise with those who are distressed by them.' Rt Hon Norman Lamb MP, Minister of State for Care and Support

'This is the most important and influential report that the Society has produced. Anne Cooke has been particularly effective in prosecuting with great success… initiatives which speak to the general public with the aim of triggering major policy changes'. Prof Peter Kinderman, President, British Psychological Society

Impact on journalists, media and public debate: *Understanding Psychosis* has been widely discussed in the UK and US media in particular and has led to the inclusion of psychological perspectives in public information and debate. Some examples follow.

Radio: As mentioned above I was interviewed by John Humphrys on the BBC Radio 4's *Today Programme*. I was also interviewed by Claudia Hammond on *All in the Mind*.

Print journalism: A New York Times piece by anthropologist Tanya Luhrmann suggested that the report 'redefines mental illness'. The piece led to significant debate in the USA about its implications for practice: see for example this piece by the former President of American Psychiatric Association and this by the Chair of its DSM-IV (Diagnostic Manual) committee. There were also a number of pieces in UK newspapers, for example Freeman & Freeman, 2014 and Allan, 2014.

I hope that the above gives some idea of my professional and academic journey to this point and situates my interest in the concept of severe mental illness. I now turn to the commentary itself.

Anne Cooke
May 2022

Part 1: Commentary on Scholarly Contribution

Developing a not-knowing approach to experiences described as severe mental illness

10062 words plus abstract and references

Acknowledgements

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I am also very grateful to my line manager Professor Margie Callanan for the creative and generous ways she has helped and allowed me to carve out time for this work.

Finally, my husband Bruce and my (now nearly adult) children have patiently tolerated my frequent physical or psychological absence whilst I worked not only on this account, but also on the other papers to which it refers. Thank you all.

Abstract

The concept of ‘severe mental illness’ (SMI) is often used to distinguish certain constellations of experience and behaviour - for example hearing voices, holding beliefs that others find strange, or appearing out of touch with reality - from other distressing experiences, such as anxiety, which appear more readily ‘understandable’. This narrative critically reviews eighteen published works which, taken together, address four related issues:

- The utility of the ‘severe mental illness’ concept as drawn on in mental health services and within society more broadly
- Possible alternatives, including psychological and social approaches and finally the ‘not knowing’ approach I have developed to theory and practice in this area, stressing the need for epistemic humility on the part of professionals
- Ways in which these alternatives are drawn on in professional practice, including by clinical psychologists, and inform interventions
- Ways in which these critiques, alternatives and interventions can be disseminated within society and incorporated into professional training.

I examine each of the above questions in the light of evidence from eighteen conceptual and empirical studies: for eight of these I was sole or first author, and for the remainder I made a major conceptual and practical contribution as detailed in Appendix 1. My review concludes that whilst it has some advantages, there are a number of problems with the concept of SMI both for those affected and for wider society. I examine possible alternative approaches, investigating how these can be used in clinical practice, and disseminated by means of professional training and public information initiatives. However, given the heterogeneity of the problems that attract the SMI designation, and the multiplicity of factors that may contribute to their origin or maintenance, any approach that makes a priori assumptions about the likely nature and causes of problems for a particular individual brings with it the possibility of epistemic violence. My particular contribution has been to develop a ‘not-knowing’ approach to these problems based not on any a priori causal model - be that biological, psychological or social - but rather on epistemic humility on the part of professionals and a collaborative approach which seeks to identify and ameliorate the unique

factors contributing to a particular person's distress. It also seeks to address the wider underlying systemic factors in a new approach to public mental health.

Introduction

The nature and causes of the experiences commonly called mental illness or mental health problems are a subject of much debate (e.g. Craddock, 2008; Johnstone & Boyle, 2018.) The approach which has been in the ascendancy for around the last fifty years makes the core assumption that puzzling experiences (such as voice hearing) and problematic emotional states (such as persistent low mood) are best understood as symptoms of illnesses (in this case schizophrenia and depression respectively) which have a primarily biological basis and can be diagnosed and treated in the same way as say, malaria or diabetes (Pilgrim, 2020b). This idea is so widespread in our society as to be unquestioned or 'taken for granted' (Andrews, 2012) by many, and particularly by many mental health professionals (Cooke, Smythe & Anscombe, 2019). In what follows it will be referred to as the *biological model*. Other terms with a roughly overlapping meaning, although used in varying ways by different authors, include the *medical, illness, diagnostic* or *disease* model. See Pilgrim (2020b) for a discussion of the various ways these terms are used and the debates surrounding them.

The concept of 'severe mental illness'

As my colleague Peter Kinderman and I have suggested (Cooke & Kinderman, 2018)[1], many people are aware of the limitations of the biological approach with respect to common experiences such as anxiety and low mood which are widely acknowledged to be often, at least in part, understandable reactions to life circumstances. However, the same does not necessarily apply to experiences such as hearing voices, holding beliefs that others find strange, appearing out of touch with reality, or experiencing extreme mood states. These phenomena are often seen as symptoms of 'severe mental illnesses' (SMIs), arising primarily from brain dysfunction (Read & Dillon, 2014). The archetypal SMI is schizophrenia, and many otherwise critical commentators (e.g. Frances, 2014, Frith, 2015) are keen to distinguish it from more 'normal', understandable, psychological problems. The grounds for this distinction appear to be both theoretical (a belief that certain experiences are markers of

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[1] This introductory paragraph is adapted from that paper, which I drafted

underlying biological illness) and practical (a wish to ensure, for example, that people receive appropriate care [e.g. Frances, 2014]).

Whilst rarely tightly defined, the SMI epithet tends to be applied where someone's experiences are seen as indicative of schizophrenia or bipolar disorder. For example, the UK National Institute for Clinical Excellence (NICE) (2019) states that "Severe mental illnesses include schizophrenia, bipolar disorder and other psychoses'. It distinguishes them from 'common mental health problems' such as depression or anxiety (NICE, 2011; 2017). In the USA, the phrase 'serious mental illness' is often used (e.g. National Institute of Health, 2021).

Despite its current dominance, the biological model has been subject to increasing challenge. Research has failed conclusively to identify 'biomarkers' for, or biological causes of most mental health problems (Kamens, 2014; Moncrieff et.al, 2022). Meanwhile a body of work has built up over the past 30 years (e.g. Bentall, 2003; Freeman et al., 2012; Johnstone & Boyle, 2018) suggesting that whilst biology plays a role in enabling all experience, even the most severe distress or puzzling behaviour can often be understood and addressed psychologically.

Beyond reliability and validity: utility

My own contribution builds on the above work. Whilst much of the latter is concerned with the lack of reliability and validity or 'truth value' of the SMI concept, my own work has concentrated more on its *utility*. Whilst this is sometimes narrowly defined as usefulness for researchers and clinicians (e.g. Kendell & Jablensky, 2003), I am concerned primarily with its usefulness or otherwise for those to whom it is applied, as well as more broadly in society. My work, described below, suggests that it has some advantages, at least within our current social system, but also does significant harm.

Alternatives to the SMI concept including a 'not-knowing' approach

Finally, my work has examined theoretical and practical alternatives including social and psychological approaches. Rather than concluding by advocating a particular alternative, my conclusion is the need for helpers to adopt a 'not-knowing' approach (c.f. Anderson & Goolishian, 1992), based on epistemic humility (e.g. Warburton, 2020) and consistent with a critical realist epistemology (Pilgrim, 2020a). To my knowledge my work is the first to examine in detail the implications of such an approach for the problems described as severe mental illness. Essentially, the approach is based on an acknowledgement that all helpers really *know* is that someone is describing particular distressing emotions or experiences, or perhaps is acting in a particular way. The rest - for example the idea that certain experiences are symptoms of particular underlying illnesses, cognitive biases or indeed trauma responses - is interpretation. Helpers come with some general knowledge and experience, but do not know in advance what will help any particular person. My suggestion is for clinicians to be honest about this, and to avoid imposing any one framework of understanding:

> The causes of a particular individual's difficulties are always complex. Our knowledge of what might have contributed, and what might help, is always tentative. Professionals need to respect and work with people's own ideas … Some people find it helpful to think of their problems as an illness, but others do not. Professionals should not promote any one view.
> (Cooke, 2017a, p. 103.)

Tufekci (2020) defines epistemic humility as 'an acknowledgement that we aren't certain of anything' (paragraph 2). It has been applied to physical healthcare (e.g. Stone, 2017) but rarely to mental health, although some recent authors (e.g. Ritunnano, 2022; Tomlinson & De Ruysscher, 2022; Watts, 2018) have drawn on the related concepts of epistemic (both testimonial and hermeneutic) injustice (Fricker, 2017) and epistemic violence (Spivak, 1988).

Aims and Methods

This paper reviews eighteen of my conceptual and empirical outputs in order to address four main research questions:

- How useful is the concept of severe mental illness, within society and particularly to those to whom it is applied?
- In the face of the problems with the concept, what might be an alternative approach/approaches?
- How can these alternatives – including the 'not-knowing' approach that I have developed - be used, and how are they drawn on in professional practice, including by clinical psychologists?
- How can these critiques and possible alternatives be disseminated within society and incorporated into professional training?

As appropriate to the questions - which largely relate to people's experiences, the meanings they attribute to them and the concepts they use to describe them (DeCarlo, 2018) - the empirical work has largely been qualitative. A qualitative approach is also consistent with my epistemological position, namely critical realism (Pilgrim, 2020a). Epistemological considerations are key in evaluating arguments about any concept. Whilst acknowledging the existence of a reality independent of human perceptions (i.e. ontological realism), critical realism emphasises the inherent subjectivity of different ways of viewing and describing the world (i.e. epistemological relativism), and the extent to which all concepts are a particular and partial representation of the phenomena that they attempt to describe.

In what follows I address each of the four questions in turn, first outlining the context (relevant concepts, debates and extant evidence) and then reviewing the contribution of my own works before suggesting what it is possible to conclude. Finally I examine implications for theory, practice, training and future research.

Question 1: How useful is the SMI concept within society and particularly to those to whom it is applied?

Context

Reliability and Validity

Many authors have outlined problems with the reliability (e.g. Read, 2013) and validity (e.g. Bentall, 2003; Johnstone & Boyle, 2018) of the SMI concept. Jablensky (2016) points to the lack of evidence that psychiatric diagnoses represent discrete entities. Moncrieff (2013) points out that no underlying biological dysfunction has been conclusively identified for any ‘functional mental illness’. These phenomena have been conceptualised in different ways across history (Scull, 2015) and across societies (Mills, 2014).

Utility

Given that the SMI idea is only one way of conceptualising the phenomena in question, and that there are significant problems with its validity, the question arguably becomes that of *utility*, i.e. the extent to which the idea is a useful one. As noted above, my work has focused primarily on its usefulness or otherwise for those to whom it is applied, rather than for researchers or clinicians. It is always possible that concepts persist because of their usefulness for those with power (Lieblich, 2020; Smail, 2005) rather than for those whom they are used to describe.

I turn now to five of my works which address this question, outlining each together with its conclusions.

Cooke, 2008

I first directly addressed the question of utility in a review chapter (Cooke, 2008). Whilst the paper dealt with the ‘mental illness’ concept in general, the focus was on ‘schizophrenia’ as a ‘prototypical mental illness’ (p.330). I concluded that whilst the concept has uses, at least within our current system - for example a mental illness diagnosis can help people to access income and support - for many these are outweighed by negative practical and psychological effects. *Practical effects* include avoidance (people avoid those described as mentally ill), harsh treatment (people treat those described as mentally ill harshly) and discrimination. I argued that the term has a social meaning - including ideas of unintelligibility, unpredictability, deterioration over time and dangerousness - which is distinct from its technical meaning as defined by clinicians or textbooks and appears resistant to attempts to ‘educate’ the public (Cooke & Harper, 2013). People designated mentally ill can also be denied certain rights: for example, they can be forcibly injected. *Psychological effects* identified included increased hopelessness, decreased confidence, an invitation to occupy the social role of ‘mental patient’, reduced agency, denial of the meaning of experiences and their relation to the person’s environment, and denial of any positive aspects. Finally I examined *effects on services,* concluding that the mental illness idea gives a misleading impression of certainty, and leads to ‘othering’ of service recipients and a narrow conception of their difficulties, overemphasises individual differences and leads to narrow conceptions of ‘treatment’. The idea of ‘lack of insight’ as a symptom frequently leads to coercion and arguably, in the case of trauma survivors or people who do not hold a medical view of their difficulties, epistemic violence. At the same time, the framing of services’ purpose as ‘treating SMI’ can lead to denial of help to those who are in crisis but not seen as ill, including those diagnosed with ‘personality disorder’ or whose self-harm is seen as ‘behavioural’.

I concluded by suggesting a number of alternative ways of both describing problems and offering help. These are outlined in the section on alternatives below.

Cooke & Kinderman, 2018

As outlined above, some authors (e.g. Frances, 2014) argue that the SMI concept is essential to differentiate what they see as ‘true’ mental illnesses with a biological basis from other more ‘normal’ types of distress. In this conceptual paper we argued that this belief is misguided, not only because of the lack of evidence for biological dysfunction but because of potential harm to those affected.

Firstly, we suggested that the ascription of problems to putative SMIs has led to frequent professional myopia regarding the events and circumstances of people’s lives that may have played a major role (Midlands Psychology Group, 2012). Examples include adversities like poverty, assault, or childhood abuse (Varese et al., 2012). We argued that the way that a ‘diagnosis’ such as schizophrenia appears to summarise the nature and causes of someone’s experience can prevent workers from asking about, and helping to address, life events and circumstances and their impact. Secondly, we argued that the idea of SMI can lead to misplaced certainty, where a medicalised view is unquestioned and both it and particular interventions are imposed on the service user. Finally, we argued that it can divert professional and political attention from efforts at prevention such as policies addressing childhood adversity. We proposed an alternative as outlined below (Question 2).

Allman, Cooke, Whitfield & McCartney, 2018

This was an empirical study based on interviews with young people who had been diagnosed with psychosis, and also with family members. For many young people, being designated mentally ill had led to what we termed a ‘catastrophic redefinition’ of their self-identity. Many described feeling defective and shameful. Some, influenced by popular representations of SMI, feared that they might become violent. This change in self-identity appeared to create a ‘perceptual filter’ whereby both the individual and family members overlooked or minimised achievements, focusing instead on being alert to ‘symptoms’. We concluded that this process could significantly limit opportunities, expectations and movement beyond an illness identity, thus acting as a self-fulfilling prophecy.

Cooke, King & Greenwood, 2016

This second empirical study was based on interviews with primary school teachers and found that they almost never broached the subject of mental health in the classroom. They gave two reasons. The first was fear: fear of people seen as mentally ill, fear of ‘getting it wrong’, of scaring children and of being criticised by parents. The second was a perception that specialist technical knowledge was required. Both appeared to be at least in part related to the idea of SMI with its implication that those affected are different, frightening and only understandable by experts. We concluded that ironically, a vicious circle might be at play whereby the dominance of this social narrative is one of the factors preventing interventions that could ameliorate it, such as effective mental health education in schools.

Bowen, Kinderman & Cooke 2019

This empirical paper focused on the diagnosis of schizophrenia, arguably the archetypal ‘SMI’. Using corpus linguistic methods (Jones & Waller, 2015), we examined ‘red-top’ newspaper articles mentioning the word schizophrenia. Analysis revealed frequent use of linguistic signatures of violence, for example language referring to: acts of violence (e.g. murder); descriptions of acts (e.g. violent); implements of violence (e.g. hammer), identity labels (e.g. schizophrenic, most commonly to name individuals who had committed acts of violence) and exemplars (e.g. Sutcliffe). We concluded that these newspapers present people with the diagnosis as 'other’ and as prone to violence. Such stereotypes arguably both draw on and perpetuate the social meaning of ‘SMI’.

Question 1: Summary and Conclusions

Taken together, the five works described suggest that despite some advantages, the SMI idea:

- has a number of harmful effects on those so designated
- diverts resources from treatments other than medication and needed efforts at prevention
- has a negative social meaning incorporating both medicalised ideas of brain disease and ideas of violence
- leads to a vicious circle where media coverage reinforces stereotypes and educators avoid the topic of mental health, leaving those stereotypes unchallenged.

This raises the question of possible alternatives, addressed next.

Question 2: In the face of the problems with the 'severe mental illness' idea, what might be some alternatives?

Context

The distressing experiences sometimes seen as SMI are undoubtedly real, and as a society we need to be able to respond appropriately both in terms of how we conceptualise them, and the help we offer. The current section addresses the former: the latter is the subject of the next (Question 3).

Psychological and social models

The alternative conceptual frameworks most often cited are the *psychological model* (e.g. Kinderman, 2005) which focuses on the way the person sees the world and interprets events, and the *social model* which views most mental health problems as normal responses to adversity of various kinds (e.g. Beresford et al., 2016). These come together in the 'psychosocial approach' which focuses on the interaction between the two (e.g. Read et al., 2013).

The biopsychosocial model

The 'biopsychosocial model' attempts to bring together biological, psychological and social factors as different elements of a whole rather than as competing explanations (e.g. Tripathi et al., 2019). Whilst promising, this approach has also been subject to critique. Firstly, as a result of the power and status of biological psychiatry, and the taken-for-granted nature of its explanations (e.g. Walker, 2016) there is always a risk that in practice a biopsychosocial approach becomes what Sharfstein (2005, para 5) has called a 'bio-bio-bio' approach, where psychological and social factors are often reduced to the status of 'triggers' for the expression of essentially biological differences. In practice this means that whilst services might be branded as, say 'holistic' or 'trauma-informed', on the ground things often stay much the same, with the new ideas being 'colonised' and practices failing to change significantly (Dillon, 2016). The biological approach is self-perpetuating both conceptually and practically, with new practitioners being socialised into it within the medical settings in which help is currently offered, and existing clinicians often arguably dependent on it for their authority and income.

In what follows I first outline three works which point to evidence that people's environments play a much larger role than often supposed in the experiences commonly thought of as psychosis or SMI. I then describe my own theoretical contribution, applying a 'not-knowing' approach, and present four works in which I have developed and elaborated it.

Papers demonstrating the role of the social environment in 'SMI'

Chisholm, Freeman & Cooke, 2006

This empirical paper, the only one of those presented here which used a quantitative methodology, was an early examination of the (since well established) links between trauma and psychosis, concluding that trauma may lead to psychosis as well as the other way round. We concluded that 'traumatic stress and psychosis can… be maintained in a bidirectional feedback loop' (p.556). Whilst widely accepted now, this was a relatively ground-breaking conclusion in 2006 and the paper has over 60 citations.

Jackson, Hayward & Cooke, 2011

This qualitative study interviewed twelve people who hear voices and have a positive relationship with them. Few viewed their voices as a symptom of illness. All had developed a coherent narrative (in most cases a spiritual one) which viewed them as meaningful. Many were part of communities, such as spiritualist churches, that supported this view. This paper has been widely discussed, with over 70 citations.

Taken together, then, the latter two studies suggest that the social environment can play an important role both in the genesis of 'psychotic' experiences and in determining whether, and to what degree, they are experienced as distressing.

Cupitt & Cooke, 2018

This theoretical book chapter summarised recent developments in psychological approaches to 'SMI'. We suggested that the processes contributing to 'psychotic' distress may be similar to those underlying other psychological problems. We argued for increasing recognition of the role of the social environment, citing for example Varese et al. (2012) who found that experiencing multiple childhood traumas appears to give approximately the same risk of developing psychosis as smoking does for lung cancer.

Going one step further, we quoted authors who are going so far as to suggest abandoning the idea of psychosis or SMI altogether:

> There is growing evidence that the experiences service users report … are, in many cases, a natural reaction to … abuses… There is abuse, and there are responses to the abuse. There is no additional 'psychosis' that needs explaining (Johnstone, 2011, p. 106).

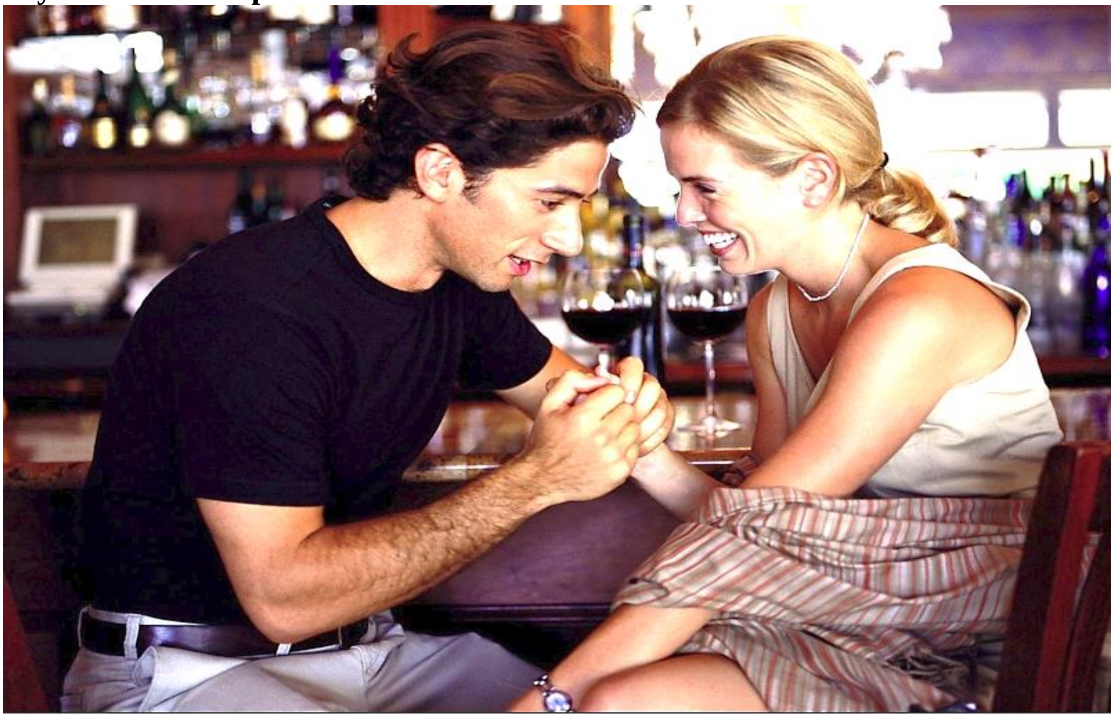
Developing a 'not-knowing' approach

In addition to empirical investigation of, and theoretical discussion of psychosocial factors in 'SMI', my contribution has included the development and articulation of a new – at least in this context - theoretical and clinical approach which I call a 'not-knowing' one. This represents my attempt to make conceptual sense of these phenomena, informed by theory and by empirical data including my own observations over the course of my career. Eschewing a-priori theories about the likely origins of 'symptoms', my approach takes as its starting point the complexity and ultimate unknowability of the often multitudinous and interacting reasons for any one human experience, including those commonly viewed as symptoms of SMI. It stresses the need for what might be called *epistemic humility* (Cooke, 2016a) or perhaps *radical uncertainty* (Cooke & Richardson, 2020) on the part of theorists and practitioners. Rather than providing expert 'diagnosis' and solutions, I see the role of clinical psychology as bringing the conceptual tools to co-construct a unique formulation with each individual – a made-to-measure approach rather than the off-the-peg one advocated by a diagnostic paradigm.

Whilst a 'not-knowing' approach is not novel (see e.g. Anderson & Goolishian, 1992) it has hitherto rarely been applied to the significant and ongoing problems which attract the label of SMI. This is probably because of the taken-for-granted status of the idea with its implication of biological causation.

In talks (e.g. Cooke & Richardson, 2020) I sometimes explain the approach using what I call the 'first date example'. I show a picture of a couple sitting at a bar:

Figure 1: Picture used to illustrate the ‘first-date example’ of the interacting reasons for any one human experience or behaviour



I ask the question: This woman is laughing very loudly. Why?

- There could be a genetic explanation - she has an inherited tendency to laugh loudly.
- Alternatively, there could be a psychological explanation. She really likes him.
- Alternatively, there could be a social explanation. They are in a pub and that is the kind of behaviour expected in a pub. It is also their first date, so they are still at the 'laughing a lot at each other's jokes' stage.
- Alternatively, there could be a biochemical explanation. She is on her sixth gin and tonic.

So which is it? The answer, of course, is that all the above are likely to be involved, constantly interacting in infinitely complex ways. I suggest that it is the same in the complex and contested area of human experience that we call ‘SMI’, and caution against simple explanations and knowledge claims.

I have outlined and developed this approach in four papers in particular:

Cooke, 2008

This chapter, described above, concluded by suggesting a number of alternative ways both of describing problems and of offering help. The former included describing experiences as such, rather than automatically interpreting them in a certain way (e.g. as ‘symptoms’) and attending closely to, and respecting, the person’s own way of describing them (i.e. a phenomenological approach). The latter included a holistic approach which addresses ‘psychotic’ experiences in the context of the person’s life rather than as separable ‘symptoms’, and a focus on helping them – and those around them – to develop narratives that make sense to them and which suggest ways forward.

One stream of work has provided a particular opportunity to develop and refine my theoretical approach, namely my involvement in British Psychological Society (BPS) consensus reports. There have been three of these relating to ‘SMI’: I co-edited two (Jones, Lobban & Cooke, 2010; Kinderman & Cooke, 2000) and was sole editor and project lead for the third (Cooke, 2014; 2017a). These projects brought together leading clinicians, theorists and researchers in an attempt to make accessible psychological perspectives on ‘SMI’. The discussions that ensued, particularly during the latter project, enabled me to think through, articulate and refine a theoretical (or perhaps meta-theoretical) approach that was both consistent with the science as I understood it, and also comprehensive enough to enable the group to achieve consensus. The latter was challenging, since in each case the author group included at least twenty leading academics with a range of - sometimes conflicting - views on the issues in question. I discuss the process by which consensus was achieved both below and in **Cooke (2016a)**. The articulation of what could be called a ‘not-knowing’ approach was key in enabling those with differing beliefs to agree a common message. I now briefly describe this process and the resulting documents.

Kinderman & Cooke, 2000

In the late 1990s the BPS Division of Clinical Psychology was keen to challenge prevailing stereotypes about ‘SMI’ and to provide a psychological perspective. I was commissioned to produce, with colleagues, a public information report. *Recent Advances in Understanding Mental Illness* warned against the idea that ‘a single cause of ‘schizophrenia’’ (p.22) would be found, stating that ‘each person’s difficulties are likely to have arisen and be maintained by a unique combination of interacting factors’ (p.34) and noting that not everyone sees their problems as an illness. This was one of the first major publications to present such a perspective. It was widely discussed and led to the production of *Psychosis Revisited*, a training package funded by the UK Department of Health (Basset, Cooke & Read, 2003). The latter became a best seller and a second edition was published five years later (Basset et. al., 2008).

Jones, Lobban & Cooke 2010

This second report again synthesised research and achieved consensus among a team of specialists. The resulting document challenged the dominant medicalised understanding of ‘bipolar’ experiences. It had a significant impact including on NICE guidelines, with first author Jones being invited to be part of the guideline group; and led to the development of a toolkit for carers (REACT: Lobban et al., 2020). Profs Jones and Lobban and I have recently been commissioned to produce an updated report.

Cooke, 2014; 2017a

I led the project to produce this third DCP consensus report, which outlined a psychosocial approach to ‘SMI’. The project involved 24 contributors, including 13 professors, drawn from 9 UK HEIs and the NHS. As editor and project lead, I brought together the originators of the various theories (e.g. Bentall and Kinderman (see e.g. Bentall et. al., 1994); Morrison (See e.g. Morrison, 2001); Garety, Kuipers and Freeman (see Garety et. al, 2001) as well as theorists from lived experience groups, for example the Hearing Voices Network (e.g. Dillon and Longden: see Dillon & Longden, 2012). Drawing on an earlier document (Kinderman & Cooke, 2000) I then drafted a 50,000-word review synthesising the various theories and proposing a ‘not-knowing’ approach as outlined above, characterised by acknowledgement of aetiological multidetermination and the consequent need for humility on the part of professionals. The report exhorted workers ‘not to insist that people accept any one particular framework of understanding, for example that their experiences are symptoms of an illness’ (p.6). There was a range of views within the author group on the issues in question but the adoption of a ‘not-knowing’ approach enabled consensus. The publication and subsequent widespread discussion of this document led to national and international impact including citation by the United Nations (United Nations, 2017) as evidence of a paradigmatic shift in the field.

In summary, then, my work as reviewed here has suggested that psychosocial factors – the events and circumstances of people’s lives and how they interpret and respond to them –

often play a significant role in the experiences commonly thought of as ‘SMI’. However, human experiences are complex and multidetermined and it therefore behooves helpers to adopt a curious, ‘not knowing’ approach. This is often counter-cultural in the medicalised settings where most care is currently provided.

Question 3: How can these alternatives be used and how are they drawn on in professional practice, including by clinical psychologists?

Context

Having established the problematic and contested nature of the SMI concept and outlined some possible conceptual alternatives including a ‘not-knowing’ approach, I will now describe a third stream of work which has examined how these alternatives can be, and are, drawn on in clinical practice. I first outline the recommendations of a theoretical book chapter (Cupitt & Cooke, 2018) and then describe four empirical studies, one based on interviews with service users and three with clinical psychologists. The first interviewed people who had used both medicalised and alternative crisis services (Prytherch, Cooke & Marsh, 2020). The second examined clinical psychologists’ use of one particular alternative approach, namely that based on the idea that ‘psychotic’ experiences, whilst often distressing, can also be transformative (Cooke & Brett, 2020). The third examined one challenge faced by clinical psychologists when drawing on alternative approaches, namely pressure to comply with guidelines based on medicalised assumptions (Court, Cooke & Scrivener, 2017). Finally, Cooke, Smythe & Anscombe (2019) examined strategies used by clinical psychologists critical of the biological model to stay working within mainstream mental health services.

Cupitt & Cooke, 2018

I drafted the final sections of this theoretical chapter on psychological approaches to psychosis, addressing implications for therapy of our analysis. We argued for a not-knowing approach and for openness to working within people’s own belief and value systems. We recommended that services should become more trauma-focused, asking about trauma as a part of assessment, and providing therapy to help people process traumatic events from their past that may have been part of the reason they developed problems. Finally, we recommended going beyond therapy to adopt a public health approach to ‘SMI’, focusing on prevention rather than just ‘treatment’. Drawing an analogy with the public health physicians who eliminated cholera from Western Europe by improving housing and drainage, and drawing on Wilkinson and Pickett's (2010) seminal work in this area, we suggested that prevention efforts should include social interventions to address child maltreatment and reduce inequality.

We also recommended that clinicians and researchers should participate in the public debate about 'SMI', helping to challenge misconceptions:

> *The fear of 'going crazy' underlies a great deal of distress…It is perhaps surprising therefore, that the idea of changing societal appraisals of unusual experience has not received more attention… as a means to reduce individual distress* (p.162).

Prytherch, Cooke & Marsh, 2020

Measures such as detention and forced medication are often seen as necessary for risk management in hospital settings (Independent Review of the Mental Health Act, 2018) where service users are often seen as lacking insight into their illness (Cooke, 2017c). However, service users often experience such measures as invasive and traumatising (Lees et al., 2014). Crisis houses attempt to provide an alternative. Some draw explicitly on alternative theoretical frameworks, for example 'Trauma-Informed Approaches' (TIAs) (Sweeney et al., 2016). TIAs explicitly recognise that many people diagnosed with SMI have experienced trauma and adversity: distress is seen as in many cases an understandable response to such experiences. Coercive measures are seen as potentially re-traumatising and as inimical to the development of the trusting relationships that are viewed as central to good care (Sweeney et al., 2018). Our study interviewed eight women who had experienced risk-management in both a hospital and a trauma-informed crisis house, about their reflections on each.

Participants described hospital as being dominated by a 'medical-custodial' approach, which they said was ineffective in managing long term safety and could exacerbate distress. By contrast the crisis house was described as using a relational approach that was felt to be more effective long term.

We concluded that by recognising the central role often played by power, control and trust in both the development of, and recovery from mental distress, TIAs appear to enable some people to work through crises safely and are more acceptable to service users. Therefore it seems important that in all localities, there is at least the option of a trauma-informed crisis service.

Cooke & Brett, 2020

This empirical paper examined clinical psychologists' views about, and use of, one particular alternative conceptual framework, namely a 'transformative' approach.

Some theories and many personal accounts suggest that some 'psychotic' crises, whilst distressing, can also be transformative, leading to growth and valued outcomes. This study explored twelve UK clinical psychologists' use of transformative models. None saw psychosis as a purely biological problem. Two held a 'biopsychosocial' view, seeing psychosis as an illness with psychosocial elements. Most either held a continuum view, in which psychosis-proneness was also associated with positive attributes such as creativity or sensitivity, or a 'fully psychological' view, seeing experiences as meaningful and/or as adaptive responses to events. Many believed that psychosis can be transformative in a broad sense, leading to post-traumatic growth. Some went further, believing that it can be a purposeful phenomenon (e.g. an attempt, albeit painful and sometimes unsuccessful, to solve problems) or even a spiritual one. Participants' perspectives influenced their therapeutic approach: those who saw experiences as purposeful were more likely to facilitate direct engagement with them and to support clients to explore potentially transformative aspects, although this represented an extension of rather than a break with usual practice.

Court, Cooke & Scrivener, 2017

This paper examined one challenge faced by clinical psychologists when drawing on alternative approaches, namely the need to comply with diagnosis (or 'condition') based guidelines. Those involved in developing UK (NICE) guidelines have, at least in the past, been instructed that evaluation of the validity or utility of diagnostic categories is not within their remit, even where, as in the case of 'schizophrenia', they are particularly contested (P.Garety, personal communication, 4th April 2000). Some clinical psychologists have been publicly critical of NICE's approach, suggesting that it is based on medical rather than psychological concepts and reifies psychiatric categories. Mollon (2010), for example argues that 'Psychologists, and the BPS, have colluded in this betrayal of our profession through an endorsement of the crude medical model of NICE' (p.130) and finds this 'deeply puzzling' (p.130).

Our paper was a grounded theory study based on interviews with eleven clinical psychologists. Participants were concerned that increasing reliance on guidelines, particularly by managers and commissioners without specialist knowledge, could reduce the availability of interventions based on individual, co-constructed formulations, and devalue clinical psychologists' particular skills in drawing on a range of conceptual resources to facilitate the latter. Participants used various strategies to manage the tension between delivering formulation-based treatment on the one hand and the pressure to comply with guidelines on the other. Notably they often did not report the former to managers, instead feeling compelled to frame their work in terms of diagnostic categories and 'NICE compliant treatments'. In discussing these findings we suggested that NICE should review its approach, including its apparent reliance on contested diagnostic constructs.

This paper was featured in the *BPS Research Digest* (Jarrett, 2016), leading to it receiving an attention rating of 189, putting it in the top 5% of outputs scored by Altmetric. A follow-up study which surveyed a larger sample and found similar concerns is currently in submission (Brownlee, Court & Cooke, 2022).

Cooke, Smythe & Anscombe, 2019

This final paper examined the strategies used by nineteen clinical psychologists critical of the biological model, to stay working within mainstream mental health services. Questions centered on the challenges they encountered in this regard, and how they managed these. Participants described their discomfort at the domination of the system by the biological model, which they saw as hegemonic and embedded in team practices and assumptions. They felt the focus was predominantly on individual deficits rather than on people's context and circumstances, and that diagnoses obscured the impact of life events. They worried that many practices replicated earlier traumas and abuses. Reflecting on the reasons that the system remains 'stuck' in the biological model, they felt that organisational structures and practices are hard to change; that medicalised discourse creates a 'language barrier' which makes it hard to articulate and share alternatives; and that in the face of complexity and extreme distress, teams welcome the (false) 'safe certainty' (Mason, 1993) that the biological model appears to offer. They also suspected that its popularity with psychiatrists was partly related to a fear of losing power and influence.

Psychologists’ responses took three forms: openly dissenting (conflict), strategically “stepping into” the biological model (compromise), or inadvertently “slipping” into it (colluding). Strategies for managing the challenges included: focusing on clients; foregrounding clients’ contexts and understandings; holding the tension between “expert” and “not-knowing” approaches; using ordinary language; forging robust working relationships; being mindful of difference and of constraints on colleagues; recognising one’s power and ability to influence; self-care and work/life balance; taking encouragement from small changes; consolidating a personal philosophy; mutual support and solidarity; drawing on scholarship and finally engaging in activism outside work. This paper provoked widespread discussion and was the subject of a news story on the *Mad in America* website (Morrill, 2019).

In summary, then, my work has identified a range of ways in which the alternative approaches described above are drawn on by practitioners, for example informing non-medical crisis services and interventions offered by clinical psychologists. Challenges include the medicalised culture of mental health services and the pressure to conform to diagnostically based guidelines. Clinical psychologists are creative in finding strategies to overcome these barriers and ensure that psychosocial alternatives continue to be available within services.

Question 4: How can these critiques and possible alternatives be disseminated and incorporated into professional training?

Context

A final stream of my scholarly work has examined how these critiques and alternatives can be disseminated within services and society and incorporated in professional training. Some of the presented works are themselves dissemination projects, intended to bridge the academy and public discourse and to make these debates accessible to a broader audience. In what follows I first outline the recommendations regarding dissemination made in some of the papers detailed above, and then describe three works that were themselves dissemination projects, together with one which described one. Finally I outline two papers which investigated dissemination as a topic of scholarly investigation in its own right.

Papers with recommendations regarding dissemination

Many of the above papers have concluded with recommendations regarding dissemination. For example, our study of clinical psychologists' use of transformative models of psychosis (Cooke & Brett, 2020) found that none of the participants had received any prequalification training in these models. There is evidence that this may slowly be changing (e.g. McGowan & Dennis, 2019).

Our study of newspaper coverage of 'schizophrenia' (Bowen, Kinderman & Cooke, 2019**)** concluded that current initiatives focusing mainly on encouraging journalists to avoid using pejorative terms such as 'schizo' may be misguided. Rather we argued that professionals should offer training and guidance to journalists with respect to debates in mental health. Some of my work (not included here) has attempted to do this (e.g. Cooke, 2015; Cooke & Scurry, 2021; Kinderman & Cooke, 2017).

Works that were themselves, or described, dissemination projects

Understanding Psychosis (Cooke 2014; 2017a) was itself a dissemination project – an attempt to summarise for a public audience some of the ideas outlined in this paper. Our aim was to provide a balance to extant public-facing information, which often presents a narrow biological perspective, for example '*schizophrenia is a chronic, severe and disabling brain disease'* (schizophrenia.com; n.d.).

In a subsequent invited editorial in the *Journal of Mental Health* (Cooke, 2016a) I described the *Understanding Psychosis* project, outlining its theoretical basis, the social and political context which led to its instigation, the process of its writing and production, and its reception and impact as outlined above.

Cooke & Kinderman (2000) and Jones, Lobban & Cooke (2010), both described above, were comparable dissemination/public information projects. In recognition of my 'public-facing work to make available good quality information about mental health' (BPS, 2017, para 1) I was named BPS *Practitioner Psychologist of the Year 2016* (Sutton, 2016).

Conceptual and empirical papers focused on dissemination

Finally, in addition to the above works that make recommendations regarding dissemination, or represent or describe my own dissemination efforts, two papers investigated dissemination as a topic of scholarly investigation in its own right.

Cooke, 2017b

This conceptual chapter examines the tensions associated with inviting trainees who are being trained at NHS expense, to question the guiding ideas behind much mental health provision, including the idea of SMI. The chapter outlines the ways that colleagues and I have managed these tensions and developed teaching in this area on a doctoral programme in clinical psychology, such that its critical 'edge' is now one of the aspects most valued by trainees (Chatfield, 2016).

Cooke, King & Greenwood, 2016

Finally, Cooke, King & Greenwood (2016) focused on dissemination within schools. This study, described above, found that conversations about mental health appeared to be absent from participants' classrooms because of the teachers' fear of 'mental illness' and their belief that only specialists can understand or comment on it. The paper concluded with a number of recommendations regarding dissemination. These included adding mental health to the national curriculum and adopting a psychological, continuum-based approach, stressing that everyone experiences mental health problems at some time and to some degree. There are signs that this approach is being adopted in some places (McGillivray et al., 2021).

Discussion

The following section summarises the work described above and how my ideas have evolved over the years. It then discusses it in the context of other work in the field and addresses its strengths and limitations, and what has made it possible. It asks what it is possible to conclude and what my particular contribution has been, and makes recommendations for future scholarly work. Finally, it examines the practical impact of the work including its influence on current services, and outlines its implications for future practice.

Summary of main findings

Firstly, my work has examined the ***utility of the SMI concept***. It suggests that despite some advantages, the concept has many negative practical and psychological effects on those to whom it is applied. Firstly, for some it can lead to a 'catastrophic redefinition of identity' (Allman et. al., 2018) and a cycle of negative expectation. Secondly, by positioning distress as a frightening illness in need of specialist diagnosis and treatment, the concept can disempower others, provoking anxiety, reducing opportunities for understanding and support and leading to 'them-and-us' thinking and unhelpful stereotypes which are both reflected in and maintained by mainstream media. Finally, it appears to lead to the domination of services by a narrow biological and sometimes coercive approach often unpopular with recipients (e.g. Prytherch, Cooke & Marsh, 2021).

Secondly, my work has examined ***possible alternatives*** including psychological and social approaches. Whilst providing support for the importance of both of the latter, my own theoretical contribution has been to articulate how a 'not-knowing' approach (e.g Anderson & Goolishian, 1992) can be applied in this context. This approach stresses the need for epistemological and aetiological humility, acknowledging the heterogeneity of problems and their aetiological complexity and indeterminacy rather than assuming the veracity of any particular lens, be that biological, psychological or social. In terms of interventions, my work suggests that more attention could usefully be paid to the events and circumstances of people's lives in efforts at prevention as well as helping. A not-knowing approach views the client as the expert on his or her own problems, and formulation and treatment are co-constructed. This is counter-cultural in services predicated on the idea that clinicians are the experts and that service users often 'lack insight' (Cooke, 2017c).

Thirdly, my work has examined ***ways in which these alternatives are drawn on in professional practice***, including by clinical psychologists, and inform interventions. It suggests that many clinical psychologists have reservations about both the SMI concept and the utility of diagnosis-driven guidelines. They are creative in finding ways to offer psychosocially informed, client-centred and formulation-based interventions within a medicalised system.

My work has also examined how crisis care can be offered and risk managed using a trauma-informed approach. By recognising the central role of power, control and relationships in both the development of, and recovery from distress, trauma-informed crisis houses appear to enable at least some people safely to work through their distress, whilst maintaining freedom and control. My work has been cited in support of campaigns to increase provision in this area (e.g. Turner, 2021).

Finally, my work has addressed ***ways in which these critiques, alternatives and interventions can be disseminated*** and incorporated into professional training. Some of my work has itself comprised dissemination projects. Information materials written in clear, ordinary language and aimed at the general public have also proved useful within training for NHS and social care staff (e.g. A. Brabban, personal communication, February 26, 2020). Professional training is an important means by which ideas and research can inform practice: my work has examined how it is possible to train workers to fill current roles and enact current mandates, whilst also educating critical thinkers and exposing trainees to ideas that challenge the status quo. With respect to educating the public, schools are likely to play a key role. My work suggests that the SMI idea may be one of the reasons that teachers often avoid the topic of mental health in the classroom. Offering a normalising, continuum-based approach may offer a way forward for mental health education in schools.

Strengths and Limitations of the work

The strengths of the presented work include a rootedness in my clinical practice and in the lived experience of the study participants. The conceptual model I have developed has provided a useful frame, and has enabled me to bridge traditional divides, for example collaborating with colleagues with a range of views and from different theoretical and clinical 'stables'. I hope that it provides a useful basis for ongoing theoretical and clinical efforts.

In terms of limitations, the described studies are mostly relatively small in scale. Many of the questions they address relate to concepts, personal experiences and meanings, and as such are best answered by qualitative methods which work with small numbers of participants but examine the material in depth. I would argue that small scale does not indicate lack of robustness, significance, or applicability beyond the immediate context (i.e. 'transferability' – see e.g. Carminati, 2018).

One obvious question is the extent to which my findings and conclusions have been influenced by my pre-existing beliefs, attitudes, hopes and commitments. As will be clear from the preface, my research has been informed by my experiences and observations as a clinical psychologist working within the mental health system, which sensitised me to the possible harms associated with a narrow biological approach. The way I have approached this issue is not by claiming to be able completely to 'bracket' my beliefs and values: whilst I have attempted to maintain a reflexive stance and have used reflexive practices such as bracketing interviews (Rolls & Relf, 2006) throughout, I agree with Fischer (2009) that complete 'bracketing' in this sense is an impossible goal:

> *Perspective can never be ruled out. We can perceive only from perspectives. Bracketing is intended to help us to identify our perspectives and to examine them* (p.584).

Instead I have approached the issue of trustworthiness (Williams & Morrow, 2009) primarily by attempting to be as transparent as possible, such that readers can judge my analysis and conclusions in the light of, among other considerations, what they know about me, my beliefs and commitments. As Harper (2003) writes:

> *I see reflexivity… as a means by which I can be made accountable for my analysis through an explication of my interests and context … (and) social identity…and a tracing through of their influence.* (p.78)

In line with critical realism's criterion of 'judgmental rationality' (e.g. Pilgrim, 2020a) the reader can form a judgement from the presented works and from this account as to the extent to which this has been successful.

Implications for clinical practice

Developing a ‘not-knowing’ approach

The ‘not-knowing’ approach I have outlined above is arguably consistent with that traditionally taken by clinical psychology, namely basing interventions on an individualised, collaboratively constructed formulation. There are differences of emphasis: the latter emphasises the role of the psychologist in providing theoretical resources, whilst the former emphasises reflexive awareness and ‘bracketing’ of theoretical and other assumptions, much as qualitative researchers attempt to do. However the two approaches share the underlying assumption that the nature of, and particular combination of reasons for any one person’s problems cannot be known a priori. This is very different from the assumption underlying much mental health practice, namely that the clinician’s role is to identify the specific illness or disorder from which the person is suffering, and to prescribe or administer the recommended treatment for that condition.

Other approaches which are consistent with a ‘not-knowing’ stance include narrative approaches (e.g. White, 1987), and Open Dialogue (e.g. Seikkula & Olson, 2003; Razzaque & Stockmann, 2016).   Developments such as the roll-out of Open Dialogue services throughout England as part of a major trial (Pilling et al., 2022) give cause for hope that these ideas might gradually permeate mainstream services. Clinical psychologists have the potential to play a major role, as suggested by some of the works described above. The *Power Threat Meaning Framework* (Johnstone & Boyle, 2018: a formal framework for conceptualising and addressing difficulties psychosocially, intended as an alternative to psychiatric diagnosis) and the overlapping *trauma-focused* approach (see e.g. Sweeney et al., 2016) are also changing practice within services and have the potential to lead to widespread change. One concern is that, as has happened with other ideas such as the ‘recovery approach’ (see e.g. https://recoveryinthebin.org) these approaches might gradually be assimilated into, and neutralised by the status quo within services. There are signs that this might already be happening with the trauma-focused approach, with some services claiming to be trauma-focused when they are not always experienced as such by their users (Webb, forthcoming). In an adaptation of Georgiades and Phillimore’s (1975) famous saying, institutional culture eats innovation for breakfast. A related concern is that within services which privilege ideas of ‘expertise’ and ‘prescription’, these approaches could begin to be used prescriptively rather than collaboratively. It is important not to replace one dogmatic orthodoxy with another. In Watts' words (2015, p.12) we need to 'wear our knowledges lightly'.

Crisis Care

Some of my recent work has explored what a 'not-knowing' approach to crisis care might look like (e.g. Prytherch, Cooke & Marsh, 2020). There are calls for a non-medical, trauma-informed crisis house in every town (Cooke, 2021; Hibbins, 2021). With strong leadership it is possible for such facilities to function inside the NHS (e.g. Cooke, McNicholas & Rose, 2019). However the cultural pressures towards medicalisation are great, especially in the current risk-averse context, and an alternative might be for them to be managed by local authorities (Kinderman, 2014) or third sector organisations (c.f. Leeds Survivor-Led Crisis Service: see www.lslcs.org.uk).

Public education: challenging taken-for-granted ideas about mental health

Despite the availability of alternative conceptual and practical approaches as described here, public and professional discourse largely continues to 'take for granted' (Galbin, 2014) the idea of SMI. Most journalists I speak to, for example, are surprised to hear that there are no blood tests for schizophrenia. My dissemination work described above aims to help change this (see Cooke, 2016a); other encouraging developments in this regard include the *Drop the Disorder* movement (Watson, 2019), the popularity of the *Power Threat Meaning Framework* (Johnstone & Boyle, 2018), and the organisations *Compassionate Mental Health* (http://www.compassionatementalhealth.co.uk) and *Safely Held Spaces* (safelyheldspaces.org). The latter has recently started running training events for journalists drawing on my work (e.g. Cooke & Scurry, 2021).

Social change: towards prevention

A move away from the automatic assumption that certain experiences are 'symptoms', and towards a not-knowing approach, has profound implications for efforts at prevention and at improving public mental health. Instead of focusing on alerting people to 'symptoms' and the need to access correct diagnosis and treatment, my analysis suggests that efforts at prevention cannot be divorced from social and political change to address issues such as inequality and the current high rates of child maltreatment. See Rahim & Cooke (2019) for more detailed analysis and recommendations.

Implications for future research and scholarship

My work also suggests a number of avenues for future scholarly work to explore.

Theoretical elaboration and empirical study of a not-knowing approach in this context

The relationship of a not-knowing approach, as outlined here, to other theories and approaches could also usefully be further explored, for example complexity theory (see e.g. Fried & Robinaugh, 2020) theories of diversity including neurodiversity (see e.g. Chapman, 2022) and other scholarship which challenges the dominant paradigm such as that by decolonial scholars (e.g. Mills, 2013) and by survivors, including those working within the emerging discipline of 'mad studies' (e.g. Russo & Sweeney, 2016).

With respect to its empirical basis, research continues to be needed into the role of factors other than biology, and the complex ways that human behaviour and experience - whether 'normal' or 'abnormal' (see Kinderman, 2017) – can be shaped. The ubiquity of the SMI idea reflects the dominance of the biological lens within our current research commissioning systems (Johnstone & Bentall, 2016). It is hopeful that at least one major funder, Wellcome, is currently interested in studies which address the complexity underlying both distress and its amelioratio(see e.g. https://wellcome.org/what-we-do/mental-health).

Researching non-medical ways of offering help for psychological distress, including crisis

Despite the scarcity of funding, further scholarly investigation is badly needed into non-medical approaches both to understanding problems and to offering help. I am continuing to investigate both (e.g. Middleton, Cooke & May, 2022) as well as examining the processes which work to maintain the status quo (e.g. De Waal, Boyle & Cooke, 2022). Work is also ongoing under my supervision to evaluate alternative approaches to crisis (e.g. Ofori-Bull, 2022).

Larger-scale, quantitative studies complement our largely qualitative exploration. Such work is being undertaken for example by Morrison and colleagues in Manchester (e.g. Longden et. al., 2021).

In addition, work is needed to investigate possible ways of fulfilling the other social functions of the SMI idea besides access to support. These include validation (a way of 'storying' distress that is recognised and respected by others) and access to income (e.g. via sick pay and benefits). A number of possibilities have been put forward by Kinderman (2014) and Johnstone & Boyle (2018) for example: these could usefully be further developed and trialled.

Researching the effectiveness of practice based on epistemic humility

The ‘diagnose-and-treat’ approach lends itself to randomised controlled trials: therapy is seen as a standardised ‘treatment’ which can be administered and evaluated in the same way as a drug. Current policy is dominated by the ‘evidence-based therapy’ movement: for example the UK’s National Institute for Health Research regards randomised controlled trials as the ‘gold standard’ (NIHR Evaluation, Trials and Studies Co-ordinating Centre, n.d.). Accordingly, these have informed recent policy such as, for example, the ‘Increasing Access to Psychological Therapies’ initiative (Binnie, 2015). In the current cultural and political context, this has led to a situation where the main intervention offered is time-limited, manualised, diagnosis-driven cognitive behaviour therapy delivered largely by non-psychologists. Criteria for the accreditation of clinical psychology programmes have changed to include the need to teach and assess skills in particular ‘brands’ of therapy (BPS, 2019). In a recent development, clinical psychology courses are to be offered financial incentives to change the content of programmes such that trainees gain ‘dual accreditation’ with therapy accrediting bodies such as the British Association for Behavioural and Cognitive Psychotherapy (Health Education England, 2022; Whittington, 2021). My work suggests that these developments bring with them the danger of the core skill and unique contribution of clinical psychology - namely the ability to draw on a wide range of theoretical and empirical resources to inform interventions based on individual collaborative formulations (e.g. Management Advisory Service to the NHS, 1989) - gradually being devalued.

It is more complex to research the effectiveness of an individualised, ‘not knowing’ approach drawing on a range of psychological theory, but such research is urgently needed. It is important that studies do not reproduce medicalised assumptions e.g. by using ‘symptom’ scores as the default or main outcome measures (see e.g. Wampold & Imel, 2015 on the need for a ‘contextualised model’ of therapy mechanism and outcome). More personalised ways of assessing outcome, such as Personal Goal Attainment Scaling, (Kiresuk & Sherman, 1968) for example, have a role to play here. Collaboration with service users will be vital to ensure that research questions, outcomes and methodologies are consistent with the values and priorities of those directly affected.

Finally, research on therapy process or mechanisms - and the ‘active ingredients’ of other forms of help such as crisis care - has been largely neglected in favour of attempts to measure outcomes. Such process research is urgently needed in order to understand which elements are most valued by recipients and lead to most positive change. Some of my own work is attempting to do this: for example a study is underway interviewing staff and users of a crisis service about their views on the elements of effective risk management (Ofori-Bull, 2022).

Final reflections

I hope that my work has made a small contribution to opening up what I see as key debates and helping to ensure that people experiencing the problems sometimes called ‘severe mental illness’ are met with compassion and understanding, and protected from the worst excesses of a ‘mental health’ system which can often be reductionist, paternalistic and, for some, harmful. It is important that people can find support, including at times of crisis, without first having to accepting an individualising, pathologising and arguably victim-blaming conceptualisation of their difficulties. I have been very encouraged to hear that my work has played a role for some in this regard (e.g. Longden, personal communication, 3 March 2014).

I hope that I have helped to make debates accessible. Not all academics find it easy to write in language that non-specialists can understand. My editing role in the various BPS reports, for example, often felt more like that of an interpreter, translating academic language into terms that are more widely understandable.

The not-knowing approach has been helpful in dealing with disagreement. It has enabled me to frame different positions in non-pejorative ways, allowing discussion and enabling the building of consensus. Even those who generally endorse biological approaches are usually happy to acknowledge that mental health is a contested area (De Waal, Boyle & Cooke, 2022). Whilst seemingly obvious, this is a very different starting point for discussions and for public information from the assertion of ‘facts’.

Collaboration has been key. I much prefer to work as part of a team, finding creativity in conversation and collaboration. Collaboration has been particularly important in helping me to maintain a questioning stance throughout my career and in generating ideas. The BPS has been particularly important in this regard, enabling me to bring together a key group of clinicians and researchers in the area of ‘SMI’. Several of this group have been frequent collaborators. Other collaborations have been with trainees on the clinical psychology doctorate on which I teach. Many of the presented works had their origin in trainee projects. Rather than present trainees with ready-formed project ideas, I prefer to allow ideas to emerge in conversation which speak to both of our interests and commitments. The final group of collaborators have been people who themselves use services, some of whom have been co-authors. For example one in four of the contributors to *Understanding Psychosis* (Cooke, 2017) had themselves experienced significant mental health problems.

I have also drawn heavily on my clinical practice – this is what inspired this research stream and as will be clear from the preface, many of my ideas have first arisen in reflection on clinical work or in conversations in clinical settings.

Social media has also been important. Whilst Twitter has its limitations and frustrations, it is not only an excellent source of information (for example highlighting new papers) but also gives a sense of the range of views on any topic in this contested field. I have learned lessons from its no-holds-barred ‘post publication peer review’ that, whilst not always easy or fair, have been useful in subsequent work.

Conclusion

Despite its limitations, I believe it is possible to draw a tentative conclusion from the body of work presented: namely that whilst it currently fulfils a number of functions such as providing a framework for help and support, the SMI concept also has significant negative effects both for those directly affected and also for wider society. A more useful approach would be an individualised, ‘not-knowing’ one where helpers work collaboratively with those experiencing problems to identify contributory factors and possibilities for change. Further theoretical and practical development of such approaches is needed. Alternative means will also have to be found to fulfil some of the functions currently fulfilled (albeit imperfectly) by the idea of SMI, namely access to validation, income and support: recent work has begun to address this question.

Change is likely to be slow because despite the problems outlined here, the SMI concept has great utility for many individuals and organisations in positions of power. Pharmaceutical companies obviously profit greatly, and some professions – most obviously psychiatry, but also others - rely on the idea for their material and social power. The SMI idea also fulfils a psychological function within society, providing a narrative that expertise is available to solve problems such as extreme distress or troubling behaviour (Rogers & Pilgrim, 2020). Nevertheless, there are signs that the debates outlined here are slowly entering the public discourse (e.g. Clare, 2021; Filer, 2019) and that alternative services are opening (e.g. McKeon, n.d.). I hope that my own scholarly contribution will continue to play a part in this.

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Appendix 1: List of submitted outputs

Listed here in descending date order. For co-authored papers, I have described my contribution and estimated the proportion of the whole it represented.

1. Prytherch, H., Cooke, A. & Marsh, I. (2021). Coercion or collaboration: service-user experiences of risk management in hospital and a trauma-informed crisis house. *Psychosis*, 13, 93-104. 2 citations. https://doi.org/10.1080/17522439.2020.1830155

This empirical study originated as a DClinPsy thesis for which I was lead supervisor. I estimate my contribution at 35%: I instigated the project both conceptually and practically, and contributed extensively to the conceptualisation and writing.

2. Cooke, A & Brett, C. (2020). Clinical psychologists' use of transformational models of psychosis: a grounded theory study. *Clinical Psychology and Psychotherapy* 27, 87-96.1 citation. https://doi.org/10.1002/cpp.2411.

I would estimate my contribution at 40%. This empirical study originated as a DClinPsy thesis for which I was sole supervisor. I then took the lead in writing it up as a journal paper.

3. Bowen, M., Kinderman, P. & Cooke, A. (2019). Stigma: a linguistic analysis of the UK red-top tabloids press's representation of 'schizophrenia'. *Perspectives in Public Health*. 139(3), 147-152. 18 citations. https://doi.org/10.1177/1757913919835858**.**

I would estimate my contribution to this empirical study at 20%. Matthew Bowen (University of Chester) took a lead with this paper and conducted the analysis. He approached Peter Kinderman and me to co-author the paper because of our previous involvement in press guidance (Kinderman & Cooke, 2017). I provided significant conceptual input to the paper as well as contributing to the writing and editing multiple drafts.

4. Cooke, A., Smythe, B. & Anscombe, P. (2019). Conflict, compromise and collusion: Dilemmas for psychosocially oriented practitioners in the mental health system.

Psychosis, 11:3, 199-211. 12 citations. https://www.tandfonline.com/doi/full/10.1080/17522439.2019.1582687 .

This empirical paper originated as a DClinPsy thesis for which I was lead supervisor. I would estimate my contribution to the finished paper at 50%: I took a lead in writing the work up for publication.

5. Cooke, A., & Kinderman, P. (2018). "But what about real mental illnesses?" Alternatives to the disease model approach to 'schizophrenia'. *Journal of Humanistic Psychology*, 58 (1), 47-71. 13 citations. https://doi.org/10.1177%2F0022167817745621.

I would estimate my contribution to this conceptual paper at 75%: I constructed the argument and drafted the paper: Kinderman commented on drafts**.**

6. Allman, J., Cooke, A., Whitfield, B. & McCartney, M. (2018). "It doesn't mean I'm useless": how do young people experiencing psychosis contribute to their families and why are contributions sometimes overlooked? *Psychosis*, 10, 1, 11 – 21. 5 citations. https://doi.org/10.1080/17522439.2017.1413129.

I would estimate my contribution to this empirical paper at 35%: it had its origins in a DClinPsy thesis for which I was lead supervisor. I took a lead in editing multiple drafts of the paper and submitted it for publication as corresponding author. This paper has an attention score of 85, placing it in the top 5% of all outputs scored by Altmetric

7. Cupitt, C. & Cooke, A. (2018) Where next for CBT and Psychosis? In Cupitt, C. (ed.) *CBT for Psychosis: process-orientated therapies and the third wave.* Routledge. 1 citation. https://doi.org/10.4324/9781315294858-9.

I would estimate my contribution to this conceptual and review chapter at 25%. Cupitt drafted the initial sections. I took a lead on drafting the final two (pp. 156 -163: A *fourth wave?* and *Beyond Therapy: a public health approach to psychosis).* We both then edited several drafts of the whole chapter.

8. Cooke, A. (2017b) *Training that domesticates or education that liberates? Tensions and dilemmas related to teaching critical psychology in the context of UK clinical psychology training.* https://doi.org/10.4324/9781315209319-13. In: Newnes, C. and Golding, L., eds. *Teaching critical psychology: International perspectives*. Routledge.

9. Kinderman, P., Allsopp, K. & Cooke, A. (2017). Responses to the Publication of the American Psychiatric Association's DSM-5. *Journal of Humanistic Psychology*, 57, 6: 625-649. 10 citations. https://doi.org/10.1177/0022167817698262

I would estimate my contribution to this historical and conceptual analysis at 20%: Kinderman and Allsopp prepared the first draft to which I then made extensive changes and additions.

10. Cooke, A. (2016a). Changing society's whole approach to psychosis. *Journal of Mental Health* (invited editorial), 25, 4,287-290. 7 citations. https://doi.org/10.3109/09638237.2016.1167861.

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I would estimate my contribution to this empirical study at 35%: the paper originated as a DClinPsy thesis for which I was lead supervisor and to which I made a major conceptual contribution. I then edited multiple drafts of the final paper.

12. Cooke, A., King, J. & Greenwood, K. (2016). "We could end up in a lot of trouble": teachers' communications with young children about mental health. *Journal of Public Mental Health*, 15, 2, 103 – 114. 13 citations. https://doi.org/10.1108/JPMH-01-2016-0006 .

This empirical paper originated as a DClinPsy thesis which I co-supervised with Prof Kathryn Greenwood. I then took a lead in writing the work up for publication. I would estimate my contribution to the final publication at 40%.

13. Cooke, A. (ed) (2014; second edition 2017a) *Understanding Psychosis and Schizophrenia: Why people sometimes hear voices, believe things that others find strange, or appear out of touch with reality, and what can help*. Leicester: British Psychological Society. ISBN 978-1-85433-748-1. 183 citations.

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I would estimate my contribution at 25%. This study originated as a DClinPsy thesis which I co-supervised with Mark Hayward, who then took a lead in writing it up for publication. I commented on multiple drafts.

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Whilst Jones led the project, I had major conceptual and practical input, writing or re-writing large sections of the document and editing it to ensure conceptual clarity. As one of the three editors, I would estimate my contribution at 20%.

16. Cooke, A. (2008). Problems associated with the concept of ‘mental illness’. In Stickley, T. & Basset, T. (eds.) *Learning about Mental Health Practice*, pp. 329-346. Wiley: ISBN 978 0 470. 15 citations.

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I would estimate my contribution at 20%: this study originated as Chisholm's DClinPsy thesis which I co-supervised with Prof Daniel Freeman, and to which I had significant conceptual input. Chisholm then took a lead in writing it up for publication, and I commented on multiple drafts.

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This was the first BPS Public Information Report. I instigated the project, brought the group together, and then co-edited the report. I would estimate my contribution at 35%.

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Coercion or collaboration: service-user experiences of risk management in hospital and a trauma-informed crisis house

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ABSTRACT

Background and aims. Improving care for people in crisis remains high on the UK government agenda. Trauma-informed approaches (TIAs) have been advocated to address concerns raised about psychiatric hospital services by service-users, particularly around the use of coercion in risk management. This study explores service-users' experiences of risk management in both hospital services and a trauma-informed crisis house.

Methods. Eight women were interviewed using a semi-structured interview schedule. Interviews were transcribed and analysed using thematic analysis within a critical realist framework.

Results and discussion. Four themes were developed. In the first two ('The Medical-Custodial Approach: They Only Think About Physical Safety' and 'Coercion is Counterproductive') participants described hospital as being dominated by a medical-custodial approach, which they said was ineffective in managing long term safety and could exacerbate distress. In the next two themes ('Talking Heals' and 'Relationships as Risk Management') the crisis house was described as using a relational approach to risk management that enabled women to maintain some freedom, privacy and control and was felt to be more effective long term. This research was carried out with a small sample and both recruitment and context likely privileged positive accounts of TIAs. Clinical implications and areas for further research are discussed.

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1. Introduction

Improving care for people in acute mental health crisis is a key demand of the service-user movement and a priority for the UK government (Parkin, 2018). The Kings Fund (2015) has reported that much crisis care is of poor quality, whilst the Care Quality Commission (the body that inspects health and social services in England) has described it as "unsafe, unfair and completely unacceptable" (Care Quality Commission, 2015). Inpatient psychiatric services, key to current provision, have been described as frightening (Rose et al., 2015) and as lacking therapeutic engagement (Stenhouse, 2011). The government has recently allocated £400 million for the development of alternative forms of crisis care (Parkin, 2018). This paper looks at one example of alternative provision, comparing it with conventional care.

Why is hospital care so frequently described as unhelpful? Research into service-users' experiences suggests that part of the explanation might lie in the dominance of a "medical-custodial" model (Prytherch et al., in press) which conceptualises mental health problems as "the same kind of phenomena as physical problems like cancer" (Johnstone et al., 2018, p. 19) and treatment focuses

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on "diagnosis … [and the] administration of drugs" (*ibid*). Some service-users report that this focus can lead to life experiences such as trauma and discrimination being ignored, leaving them feeling judged and disrespected (Lees et al., 2014).

Of particular concern is the widespread and increasing use of coercive measures such as compulsory admission, restraint and forced medication (Independent Review of the Mental Health Act, 2018). Within a medical-custodial model, such measures are seen as necessary for risk management. However, service-users often experience them as humiliating, invasive and traumatising (Lees et al., 2014).

In an attempt to address some of these problems, some services have made a conscious effort to draw on alternative practice frameworks, for example, "Trauma-Informed approaches" (TIAs) (Sweeney et al., 2016), which developed out of psychological models of trauma (e.g., Herman, 2015; Van Der Kolk, 1987). TIAs recognise that many people who come into contact with mental health services will have experienced trauma and adversity, and that their distress is in many cases an understandable response to such experiences. TIAs also attend to the social, political and cultural context within which adversity is experienced.

Since trauma often occurs within the context of relationships, TIAs view collaboration and trusting relationships as central to healing (Sweeney et al., 2016). Coercive measures are seen as potentially re-traumatising and as inimical to the development of trusting relationships and therefore to good care (Sweeney et al., 2018). However, this raises the question of how risk can be managed within a trauma-informed framework.

1.1. Aims

This study aimed to explore people's experiences of risk management in both hospital services and a trauma-informed crisis house. Within the UK's National Health Service (NHS) alternatives to hospital include home treatment teams and crisis houses (Parkin, 2018). Crisis houses offer intensive, voluntary treatment within a more homely residential setting than is possible in hospital, but like hospital services, their approach can vary. Participants in the current study were interviewed about their experience of one particular crisis house in North London, which states that it uses a TIA. All participants had also experienced admission to hospital, with experience of many different hospitals between them.

2. Method

2.1. Design

Thematic analysis (Braun & Clarke, 2006) was used to analyse semi-structured qualitative interviews within a critical realist framework (Collier, 1994). The latter assumes that participants offer accounts of their experiences that have been constructed and reconstructed through memory and language. Accounts are seen as influenced by research context, wider social and political factors, and the researchers' own beliefs, but nevertheless as giving valuable insights into the phenomena described. The authors of this paper believe that the medical-custodial approach is overused and value trauma-informed care. The reader is invited to take this into account in judging the analysis and conclusions. See below and Prytherch (2018) for further details of design and analysis.

2.2. Procedure

2.2.1. Ethical Considerations

Research was conducted in line with the British Psychological Society's Code of Ethics and Conduct (British Psychological Society, 2009). An NHS ethics committee and the Camden and Islington NHS Trust approved the research.

2.2.2. *The setting*

The research took place in an NHS crisis house where all staff and residents are women. This service was set up in response to concerns regarding some women's emotional and physical safety in mixed-gender services, particularly given the high proportion of female service users who have experienced abuse from males (Cooke et al., 2019). One major criterion for admission is that a woman is otherwise likely to be admitted to hospital: a previous study found that most women admitted to the crisis house had had previous hospital admissions (Killaspy et al., 2000). If risk is felt to be too high to be contained in a voluntary setting, women are transferred to hospital, sometimes under the Mental Health Act. This happens approximately once a month.

The service runs on trauma-informed lines but is also open to those who have not experienced trauma. The staff team is appointed on the basis of their skills, attitudes, knowledge and experience rather than professional qualifications. All staff are trained and supervised in the TIA and the initial assessment includes routine inquiry about trauma. There are 18 full-time equivalents in the team who work on a shift basis. The senior members of staff have usually worked directly within mental health services in the past but also the majority will have completed some form of psychological training. When required, medical reviews are requested from medical doctors within the crisis team. When possible, the crisis team will send a female member of staff and when this is not possible, residents are asked whether they would be willing to meet a man. Staff also work closely with GP's to support women to have up-to-date prescriptions. There are 12 places within a residential setting and women stay 2 weeks on average, though the maximum stay is 4 weeks.

Risk is managed through psychological (safety planning, regular one-to-one sessions, agreed phone calls and check-ins) rather than physical containment, recognising the key role played by relationships and the potential for coercive measures to be re-traumatising. All care is consensual and rather than "observations", there are regular "contacts" where staff check-in verbally with women. Women have keys to their rooms and staff only use master keys if they have knocked three times and had no response. Service-users have been involved in the design and management of the service from the beginning. Self-referrals are accepted and care is planned consensually by the woman and her worker. Staff anxieties regarding risk are managed through clear structures and procedures, and through the constant availability of other team members working together and based in the same office within the house. For further details about the crisis house see (Cooke et al. 2019).

2.2.3. *Recruitment*

Eight women were recruited. Five current residents were approached by crisis house staff, two of whom volunteered to participate. Four previous residents volunteered after hearing about the research through a support group based at the crisis house which is open to all previous residents (approximately ten attend per week). Finally, two previous residents volunteered after hearing about the research through a women's strategy group (a core group of six service-users plus staff who aim to raise awareness of women's issues across the Trust). See below for a discussion of the possible implications of the sampling strategy.

2.2.4. *Participants*

Participants were aged from 22 to 53 years. Five were White British, one was British Chinese, one Black African and one Greek Cypriot. All had stayed at the crisis house within the last year. All had also been admitted to hospital within the last four years (except one whose most recent admission was 9 years previously). However, none had been transferred from the crisis house to hospital during an admission.

2.2.5. *Interviews*

Interviews took place at the crisis house and lasted approximately 1 hour. Participants were asked about their experiences in the crisis house and in hospital services (see Prytherch, 2018 for interview questions). All interviews were audio-recorded. Pseudonyms have been used to protect confidentiality.

2.3. Data analysis

The analysis followed Braun and Clarke (2006) guidelines for thematic analysis. Analysis was a recursive process, involving movement backwards and forwards between stages. Stages included reading the transcripts, forming codes, clustering codes together under central organising concepts and "re-looking" at the data for "disconfirming instances" (Fischer, 2009). Given the scarcity of previous research in this area, an inductive approach was adopted. Whilst there is debate in the field about how many items are required to achieve "theoretical saturation", Braun and Clarke (2019) argue that the concept of "theoretical saturation" is rooted in positivist epistemology and not consistent with a critical realist framework. As such, rather than aiming for "theoretical saturation", these findings are presented as one interpretation that is "far enough along to make a contribution to our evolving body of understandings" (Fischer, 2009, p. 586). The sample size is comparable to that in similar studies (e.g., Ruddle, 2017). The analysis was sent to all participants, five of whom replied, all confirming that they agreed with the analysis. Yardley's (2000) quality guidelines were followed. For example, an independent researcher reviewed one coded transcript, a reflexive research journal was kept throughout and three bracketing interviews were carried out. Please see Prytherch (2018) for a full description of this process.

3. Results

Four themes were developed, the first two of which related to participants' experiences of hospital and the last two to their experiences in the crisis house. The first theme was *The medical-custodial approach: they only think about physical safety*. Whilst some participants felt that medication was helpful and that coercion kept them physically safe in the short term, they described having little space in hospital for the talking that they felt was necessary for long term healing. The second theme was *Coercion is counterproductive*. Participants felt that the coercive practices they experienced in hospital could actually make things worse through replicating past traumas and undermining the development of trusting relationships. The third theme, *Talking Heals* describes the processes that facilitated the development of trusting relationships in the crisis house and the healing nature of such relationships. The final theme *Relationships as risk management* describes how trust was used to manage risk in the crisis house and why this approach may be more effective long term. In relation to the latter two themes participants also named a number of limitations to the approach used in the crisis house.

3.1. The medical-custodial approach: they only think about physical safety

All participants felt that in hospital the focus was on medication. One explained: "it's just like 'would you like some medication or would you like to f-off?' basically" (Jo). Participants also described various forms of coercion. For example, women described having their belongings confiscated and one reported being strip-searched. They explained that the bedroom doors had "peep-holes" (Jess) and staff could "barge in without even knocking, even while you're getting undressed" (Grace).

Allison: We'll have to wait half an hour for them to go and unlock the toilets … All the rooms are locked, the kitchen is locked … it's literally worse than prison.

The majority of participants described having been "on observations":

Jess: I spent most of my time on observations, which is where there's one or two members of staff with you at all times including when you're showering, going to the toilet and you just feel so humiliated and embarrassed.

Four reported having been physically restrained and forcibly medicated.

Alix: it's written into law … they have the right to be physical, to make you ingest things that you are not willing, inject you with stuff that will make you compliant.

Participants were generally critical of this approach. Although three felt that a "chemical imbalance" (Allison) might contribute to their difficulties, all participants saw their problems as partly or completely caused by experiences of adversity. They wanted to be able to talk about their experiences, but this had not been possible in hospital.

Jo: I do think medication is necessary for a lot of people, it's definitely necessary for me … but I don't think people should be just treated with medication … healing someone [requires] dealing with everything that happened before.

Participants described how the dominance of the medical-custodial approach appeared to prevent staff "thinking about the reasons that people were acting the way they were" (Jo) and meant that staff were less likely to make time for talking.

Grace: Even the really good [staff] didn't want to sit and talk. They just felt that it wasn't their job … it was just their job to monitor people and if someone is having a hard time, the first port of call would be reach out for the medication.

Jess: In hospital, it's not about talking, about working through … why you're feeling like this, it's literally about keeping you on medication and making sure you're alive.

Whilst participants acknowledged that the medical-custodial approach was often effective in "physically keeping people alive" (Jo), they did not feel that it was effective in managing risk long term because there was no space to "deal with anything on an emotional level" (Jo).

Ruth: You get so much talk about safety and they only ever mean physical safety and I don't think that you can have that without emotional safety.

3.2. *Coercion is counterproductive*

Participants also described how coercive practices could potentially be harmful. Firstly, participants felt that the restrictive environment made them feel worse because it "basically just like emphasises how ill you are" (Jess). Secondly, two participants raised the issue of institutionalisation. Jess explained that her risk fluctuates all the time, so if she was admitted every time she felt suicidal, she would be detained continuously and "never have a chance to get better".

Jo: I've been very shocked by the way that people get so deeply institutionalised to the point where it's like impossible to break out of the system but the system's making you more ill … People die really slowly and really painfully, being admitted over and over again, using up services and using up tons of money.

Thirdly, as Ruth explained "a lot of people who have … mental health problems as adults, it's cos there's been situations in your life where you've had no power, when you really needed it". She described how for her (and in her view for many others), self-harm was a means of regaining some control. Therefore, being "trapped" (Jess, Alix) on a ward, with staff having "taken everything away" (Jess), often replicated the sensation of "complete powerlessness" (Ruth) which they felt had played an important role in their distress. Jess felt that this feeling of being trapped and powerless often led her to "resort to worse coping strategies or … get more and more desperate to a point that I might feel more impulsive to kill myself". Indeed, a number of participants described the coercive practices of detention and forced treatment as "re-traumatising" (e.g., Grace, Alix) and others used words such as "assault" (Ruth) and "torture" (Allison). They felt that such practices could "exacerbate the situation" (Jo) and that if more effort was made to meet people's emotional needs, much coercion "could be avoided" (Grace).

Alix: It's traumatic, you just get re-traumatised by your own treatment.

Many participants had experienced violence at the hands of men in the past and therefore found it particularly "re-traumatising" (Grace) when coercive measures, such as one-to-one observations (which are compulsory even if the person objects to them) were implemented by male staff.

Ruth: I don't understand why anyone would think it was OK to tell a woman who's just been sectioned 'Ok go quietly to bed while a strange man watches you sleep'. Like, sorry, what? Just cos he's got an NHS lanyard doesn't mean he stops being a man with access to your bedroom.

Finally, participants emphasised that coercive practices undermined their ability to trust staff. They felt that this increased risk as they were then less likely to seek support from staff when they felt distressed.

Ruth: I'm never gonna trust someone who I know can hold me down …

Allison: Sometimes I feel suicidal but I can't say it because … they'll keep me in … I have to almost put on an act and pretend that I'm well in order to get out so that I could kill myself.

3.3. *Talking heals*

All participants valued the regular one-to-one meetings offered in the crisis house. These were always with one of their two allocated workers and women felt this consistency enabled relationships to develop. Many of the women had experienced violence perpetuated by men and found that being in a women-only environment felt safer and made it easier to "open up [to staff] … about anything … the sexual abuse or anything" (Yinka). Staff were described as "caring" (Yinka), "compassionate" (Jo), "non-judgemental" (Jess), "respectful" (Grace) and "genuine" (Allison). Grace put this down to management and supervision structures.

Grace: I think it's the management and … staff supervision they have and kind of really embedding the whole model.

Through building relationships with, and telling their stories to staff who gave their "undivided attention" (Yinka) participants started to feel "valued as an individual" (Yinka) and to talk about things they had not spoken about before.

Alix: [Suicide] just becomes something that can be spoken about here … they violate the rule, like the first rule of suicide is don't talk about suicide. You can just have these conversations.

Yinka explained that "talking about it, all the experiences that I had … made me feel … so much better", whilst others said that it helped them to "realise … what I lacked … growing up" (Allison) or to "understand why I get suicidal" (Jess).

Two participants reported that being directly asked about trauma during the assessment had felt difficult at first. Grace explained "I got paranoid about why they wanted to know so much about me" whilst Ruth, who had not previously identified as a trauma survivor, worried that "I don't have any right to … have these problems because other people have had these experiences and I haven't". Both participants stressed that eventually, being asked helped them to name and talk about past abuse that either they had not thought of in such terms, or had kept "in a really tight kind of locker in [their] mind" (Grace). Although Ruth had found that it "really hurt when I made that connection … and created a lot of … anxiety around … urgh is this a label that I can use?", she emphasised that "it matters to be able to use words that accurately say what happened to you and to be able to acknowledge it".

Most participants said that this focus on relationship building, combined with the feeling that they were genuinely involved in decisions about their care, made it "at least possible to trust [staff] … obviously it's never guaranteed but at least it is a possibility" (Ruth). Trusting relationships were described as healing through facilitating connections with other people and through providing a powerful context for validation.

Jo: Mental illness in general is a very isolating experience … people need connections with other people … to get better (Jo).

Ruth: I think someone you trust saying … "you were a child, like it's never going to have been your fault" – it's different when it comes from someone you trust.

However, two participants also noted that talking had its limits. Claire explained, "it might help to talk to someone … but you're not gonna get a rapid f** change … unless people are here to get rehoused". Similarly, although a number of participants felt that staff at the crisis house did "really care about the social aspect of … life" (Grace), Grace pointed out that the interventions were still mainly focussed on the individual and therefore did not address the wider societal injustices that contribute to distress.

Grace: I get really angry about it. And it helps to be angry. But … I'm still being ostracised by society because I'm on benefits.

3.4. *Relationships as risk management*

When asked how they kept themselves safe in the crisis house, most participants referred to the trusting relationships that the approach enabled them to build with staff. For example, they felt able to talk about their distress, to hand blades in or to ask for support when they needed it.

Grace: It was about building that kind of relationship and being able to trust them enough to go and approach them when I was feeling like … harming myself.

Ruth explained how through this approach to risk management, participants "reach a point where they start wanting to keep themselves safe" and described this as "the only way to manage risk long term".

Allison: Here, I was given a choice that you can take [an overdose] but we'll support you not taking it … Whereas if it was in a hospital it's like I want to take an overdose but I physically can't do it.

Because risk was managed through trusting relationships rather than physical containment, participants were able to enjoy more freedom, privacy and comfort in the crisis house than in hospital. This was felt to contribute to healing. For example, the house itself was described as "homely" (e.g., Yinka) and "comfortable" (e.g., Claire). Participants appreciated having keys to their rooms and described the "knock three times" policy as "respectful of your privacy and dignity" (Grace). Finally, participants felt that being able to leave the house (with safety planning beforehand) enabled them to maintain social roles such as employment, which could be an important source of self-worth and help avoid institutionalisation.

Jess: you've got the support but you're also encouraged to keep doing what you would usually be doing, you're not in a complete bubble.

However, five participants also pointed out that the approach used in the crisis house was not able to contain all forms of risk. Jess explained that if a service-user was unable to abstain from alcohol or unprescribed drugs, then she would not be allowed to stay. Ruth explained that the crisis house is only able to function as it does because "they kind of have hospital as a back-up" and Alix said she had seen people being sent from the crisis house to hospital.

4. Discussion

This study used thematic analysis to explore eight participants' accounts of risk management in a trauma-informed women's crisis house and in psychiatric hospitals. Participants described hospital care as being dominated by a "medical-custodial model", which they felt prioritised medication and short term, physical safety. In contrast, the crisis house was described as prioritising the development of relationships and long term emotional healing. All participants believed that their distress was at least partially linked to difficult interpersonal experiences, and felt that the opportunity to talk about these in the context of trusting relationships was essential to recovery. Coercive practices, which were described in hospital services only, were viewed as potentially harmful and as undermining the development of trusting relationships; therefore, unhelpful in managing risk long term. In the crisis house however, participants described how through the formation of trusting relationships, they started to develop both the will and ways to keep themselves safe.

Most participants said they had experienced interpersonal trauma and felt that trusting relationships were therefore central to healing. This is consistent with trauma-informed theory (Sweeney et al., 2016) and echoes the findings of Pilgrim et al. (2009), who, in their summary of 50 years of interdisciplinary evidence, concluded that relationships are central in the creation and amelioration of mental health problems. However, consistent with previous accounts (Lees et al., 2014), participants felt that the emphasis in hospital had been on medication and physical safety, often through the use of coercive measures. Whilst most found medication helpful, and agreed that the coercive measures kept them safe in the short term, they felt that the dominance of this approach left little time for relationship-building or talking; again echoing previous findings (Stenhouse, 2011).

More concerning were participants' explanations of how coercive measures could at times exacerbate distress; being experienced as traumatising, as reminiscent of previous abuse and as sometimes leading to increased suicidality. These reports, which are in line with previous findings (Sweeney et al., 2018), may be explained by evidence that loss of control is often a central feature of traumatic experience (Blanch et al., 2012) and that the "power-over" relationships inherent in coercive practices can be similar to the power dynamics often at play in situations of abuse and trauma (*ibid*). Most women had experienced violence perpetuated by men, a phenomenon which is well documented (WHO, 2017). As such, and in line with previous findings (Archer et al., 2016; Blanch et al., 2012), coercive measures were described as particularly traumatising when carried out by men. Finally, in line with both trauma-informed theory (Sweeney et al., 2016) and previous empirical research (Sibitz et al., 2011), some participants reported feeling unable to trust staff who made use of coercion. Given the central importance of trusting relationships in emotional healing (Pilgrim et al., 2009), there appears to be a risk therefore that such measures could at times actually hinder the processes required for long term healing. Indeed, Krawitz et al. (2004) have warned that "frequent or lengthy use of mental health legislation [and] custodial interventions can make it more difficult for clients to work (collaboratively with clinicians) on how to reduce their risk and keep themselves safe" (p. 12).

In contrast, participants described the approach used in the crisis house as enabling the development of trusting relationships. In line with the principles of TIAs, participants described having regular opportunities to talk to staff whom they felt were compassionate, consistent and interested in the psychosocial context of their distress. Consistent with previous findings (Ciclitira et al., 2017), participants said they felt safer with, and more able to open up to women, and therefore appreciated that the service provided a women-only environment.

As well as being healing in themselves, participants described relationships as an effective way of managing risk as they felt more able to seek help when feeling unsafe. This approach to managing risk also meant that women were allowed more freedom, control and privacy and were able to maintain social roles and relationships that were important to their well-being. A sense of control, supportive relationships with family and friends and engaging in meaningful social and occupational activities have all been shown to contribute to recovery (Tew et al., 2012). The idea that taking risks in the short term – or "allowing" service users more responsibility for their risk – might reduce risk long term is not new. Krawitz et al. (2004) have referred to this approach as "professionally indicated short term risk-taking" and argue that it can be appropriate for people with a well-documented pattern of chronic suicidal or self-harming behaviour. They emphasise the importance of undertaking a thorough risk assessment, having a strong client–clinician relationship, collaboratively agreed treatment plans and shared clinician decision-making.

4.1. Limitations of trauma informed approaches within a crisis house setting

One participant who had initially not identified as having experienced trauma or adversity said that regularly being asked about trauma had at first made her feel that she did not deserve to be experiencing distress. Although she later identified as a trauma survivor, this comment highlights that those who do not identify as such, might experience the approach taken in the crisis house as invalidating their distress. Read et al. (2007) have offered advice on how to sensitively ask about traumatic experiences. They highlight the importance of asking about specific events, rather than using the terms "abuse" or "trauma", pointing out that many people may not have thought of their experiences in such terms.

Participants pointed out that only women who are considered able to keep themselves safe within the approach offered by the crisis house are offered a place. Those who are not may be admitted to hospital, sometimes under compulsion. Some might argue then that even within the trauma-informed crisis house, coercion still exists, albeit it covertly through the possibility of being referred to hospital. Indeed, critics have questioned whether contact can ever be truly voluntary within a system where involuntary detention and treatment exists (Szasz, 1970).

The fact that the crisis house, unlike hospital can reject referrals also highlights that hospital services may be tasked with supporting people with the greatest levels of distress and some may argue that this makes coercive practices necessary. However, as May (2008) points out, it is difficult to know how much risk could be managed using a non-coercive approach, because it is so rarely tried. In the present study, it was demonstrated that some serious crises can be managed safely through a less coercive approach. It is likely that, had the crisis house not been an option, most of the participants would have ended up in hospital. One of the criteria for admission to the crisis house is that a woman would otherwise be admitted (Cooke et al., 2019). Given that many said that they would never again consent to hospital admission, this admission would presumably have involved coercion. Therefore, whilst this study does not provide evidence that the needs of all those who are admitted to hospital could be met in a trauma-informed setting, it does suggest the availability of such alternatives could reduce the need for coercive approaches to risk management.

4.2. Study limitations

This research is based on only eight women's accounts. All were recruited through the crisis house where the interviews took place. Participants who found the trauma-informed approach unhelpful are less likely to have maintained contact with the service or have been willing to return there for interviews. As such, whilst it is hoped that the research might be of relevance to others, particularly given the high rates of trauma experienced by users of mental health services (Johnstone et al., 2018), the findings are unlikely to be generalisable to all those in crisis. The sample was representative of those who use the crisis house in terms of age but people of colour were under-represented. Effort was made to recruit a more mixed sample but this was unsuccessful (the three participants who declined participation were of black-African or black-Caribean heritage).

Whilst the researchers used ongoing reflexivity to identify and challenge the perspectives through which meanings evolved (see Prytherch, 2018 for details), inevitably the analysis will have also been coloured by our own beliefs and values, as stated above.

4.3. *Clinical implications*

Whilst standard treatments and practices in relation to mental health crises are generally assumed to minimise risk and optimise chances of recovery (e.g., Anon, 2017), the results of this study question these assumptions. The findings suggest that for those who have experienced trauma, many practices that are viewed as necessary within the dominant medical-custodial model can be experienced as unhelpful or even damaging. However, by recognising the central role of power, control and trust both in the development of, and recovery from mental distress, TIAs appear to enable some people to safely work through their distress, whilst maintaining freedom and control. Therefore, whilst such approaches may not be suitable for or desired by all in crisis, it seems important that in all localities, there is at least the option of a trauma-informed service. The availability of such services may also help to address current concerns over the high numbers of involuntary hospital admissions in the UK (Independent Review of the Mental Health Act, 2018) as some people who are not willing to go to hospital and are therefore currently being detained involuntarily, may consent to staying in a trauma-informed service.

Of course, creating new services is complicated given the current financial limitations of the NHS. Moreover, there may still be a need for some services that offer the containment of a locked environment. Therefore, it may also be useful to think about how trauma-informed ideas can be incorporated into current services. Examples might include training staff in the importance of relationships as an active part of treatment; using “observations” as an opportunity for engagement, rather than just for risk management; recruiting staff with knowledge, skills and experience in TIAs where possible; allocating two key workers for each patient and ensuring at least one of these is on shift at all times; where possible, meeting patients’ preferences regarding the gender of their key-workers (and other key characteristics); and finally, knocking on doors before entering, to respect patients’ privacy and dignity.

4.4. *Research implications*

This is the first study to explore service-user experiences of risk management in standard hospital care and in a trauma-informed crisis house. Future research could build on this by examining experiences of other such services. In order to seek alternative perspectives, people who specifically chose hospital over a crisis house, or those who were sent to hospital from the crisis house could be interviewed.

5. Conclusion

In the context of the current focus on improving crisis care, this study used thematic analysis to explore eight women’s experiences of risk management in hospital and in a trauma-informed crisis house. Findings suggested that for those with a trauma history, some of the practices associated with the medical-custodial approach, which participants described as dominating standard care, could be experienced as unhelpful or even damaging. In contrast, the practices prioritised by a trauma-informed approach were described as enabling the development of trusting relationships, which were felt to be central both to risk-management and long term healing. This research was carried out with a small sample, and both recruitment and context likely privileged positive accounts of TIAs. Nonetheless, given the high rates of trauma experienced by people who use mental health services, it is hoped that the findings of this study may be relevant to others in crisis. Future research could interview participants with a range of experiences as well as exploring further how TIAs can usefully inform the development of crisis care.

Disclosure statement

No potential conflict of interest was reported by the authors.

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RESEARCH ARTICLE

Clinical psychologists' use of transformative models of psychosis

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Abstract

Some theories (e.g. Jackson's Paradigm Shifting Hypothesis) and many personal accounts suggest that some psychotic crises, whilst distressing, can also be transformative, leading to growth and valued outcomes. However, little is known about the extent to which this idea informs mainstream mental health care. Clinical psychologists are influential advocates of psychosocial approaches more broadly: This study explored their use of transformative models. Twelve U.K. clinical psychologists were interviewed: Transcripts informed a grounded theory. No participants saw psychosis as a purely biological problem where the content of experiences is irrelevant. Two held a "biopsychosocial" model, viewing psychosis as an illness with psychosocial elements. Most either held a continuum view (i.e., schizotypy), in which psychosis proneness was also associated with positive attributes such as creativity or sensitivity, or a "fully psychological" view, seeing experiences as meaningful and/or as adaptive responses to events. Many believed that psychosis can be transformative in a broad sense, that is, lead to "post-traumatic growth." Some went further, believing that it can be a purposeful (e.g., an attempt, albeit painful and sometimes unsuccessful, to solve problems) or even a spiritual phenomenon. Participants' perspectives influenced their therapeutic approach: Those who saw experiences as purposeful were more likely to facilitate direct engagement with them and to support clients to explore potentially transformative aspects. However, this represented an extension of conventional approaches rather than being qualitatively different. More research is needed to clarify how widespread this approach is, to explore its utility, and to establish for whom and when it may be appropriate.

KEYWORDS

Clinical psychology, crisis intervention, post-traumatic growth, psychosis, psychosocial intervention, transformative crisis

1 | INTRODUCTION

> *The journey of awakening ... can also be a fast admission ticket into the world of psychiatry*
>
> (EmergingProud, 2017)

> *Only in the Western world have we developed this bizarre idea that hearing voices and having strange ideas has no meaning at all*
>
> (Prof John Read, 2017)

> *Psychosis involves … an attempt to reorganise to address problems*
>
> (Ron Unger, 2017)

1.1 | Debates about the nature of psychosis

There is a debate about the nature and meaning of the experiences sometimes called "psychosis" (Cooke, 2017). The dominant, medicalized approach conceptualizes them as resulting primarily from brain pathology (e.g., American Psychiatric Association, 2018). The last 30 years have seen extensive critique of this idea on both theoretical (e.g., Morrison, 2001; Williams, 2012) and practical grounds (Cooke & Kinderman, 2017). Recent evidence also suggests that antipsychotic medication may be less effective than previously thought and its potential adverse effects greater (see Moncrieff, 2013; Morrison, Hutton, Shiers, & Turkington, 2012). Some of the strongest criticism has come from the psychiatric survivor movement (e.g., Burstow, 2015; Russo & Sweeney, 2016). An alternative, psychosocial approach (see Cooke, 2017) has gained in popularity over recent years. This proposes that the way people interpret anomalous experiences is affected by their previous life experiences and the way that they have responded to and made sense of them. Psychological therapies appear to be effective (Cooke, 2017), with trials of cognitive behaviour therapy, for example, yielding effect sizes comparable with those of medication (Morrison, 2019).

1.2 | Psychosis as meaningful and potentially transformative

An experience of psychosis is often traumatic and frequently constitutes a crisis both for the person involved and for their family and friends (Chisholm, Freeman, & Cooke, 2006). However, various sources, particularly first-person accounts, suggest that psychosis can also have positive aspects (e.g., Borges, 2017; Kiser, 2004) and that psychotic crises may have the potential to bring about positive change for the person concerned (Brett, 2010). Some writers emphasize its potential role in the processing and healing of past traumatic experience (Dillon, Johnstone, & Longden, 2012). Jackson (2010) has suggested that psychotic phenomena may occur as a form of "cognitive problem-solving" process, such that situations of psychological impasse may trigger anomalous experiences that create shifts in the individual's cognitive schema and help resolve the dilemma.

1.3 | Psychosis and spiritual crisis

Spiritual content and meaning are frequently ascribed to psychotic experiences by those who experience them (Clarke, 2010; Geekie & Read, 2008). Some view episodes as profound spiritual or existential crises that can lead to important insights and positive change (Borges, 2017). Others describe their personal spirituality as a source of strength and meaning within suffering, which is important to their recovery (Campbell, 2010).

Key Practitioner Message

- Evidence suggests that some "psychotic" crises, whilst painful, can also be transformative, leading to personal growth and valued outcomes.
- Professionals who are mindful of this possibility may be more open to discussing the potential meaning and value of psychotic experiences.
- The transformational approach represents an extension of conventional psychosocial approaches to psychosis rather than a departure from them.

In addition to personal accounts, there is also a body of theoretical literature linking psychosis and spirituality (e.g., Assagioli, 2000; Brett, 2010; Clarke, 2010; Hartley, 2010). The Spiritual Crisis Network suggests that "a mental health crisis can be a wake-up call, our psyche's attempt to heal itself … an opportunity for healing and growth" (Maisel, 2016).

Some theorists view *all* forms of psychosis as inherently transformative. Others consider that some "psychoses" are misdiagnosed spiritual crises whereas others are better explained using a psychiatric or psychological framework.

The extent to which phenomena are experienced as positive—or as painful but ultimately helpful—rather than just distressing appears to depend to a large extent on the context. If those around someone are accepting of their experiences, the person is less likely to become distressed or to need help from services (Brett, 2010; Heriot-Maitland, Knight, & Peters, 2012; Jackson, Hayward, & Cooke, 2011). Examples of such contexts include some religious groups and other subcultures such as the spiritualist movement. Many nondistressed voice hearers in Jackson et al.'s (2011) study, for example, identified as mediums. The person's beliefs about their experiences appear to play an important role: Those who see their experiences as normal and understandable are less likely to be distressed by them (Lovatt, Mason, Brett, & Peters, 2010).

It is not always the experiences themselves that are seen as helpful or transformative: For some people, it is the clarification of values and priorities that can follow a profound experience of suffering and disintegration (Razzaque, 2014).

1.4 | Therapeutic approaches

The above theoretical developments have generated a number of related approaches to crisis intervention and therapy.

1.4.1 | Mainstream psychological approaches

Current guidelines recommend that people experiencing psychosis should be offered cognitive behavioural therapy (National Institute for Health and Care Excellence, 2014). This focuses on the person's interpretation of events, supporting them to check out their fears (Steel & Smith, 2013). "Third wave" approaches that incorporate mindfulness are also gaining popularity (Clarke & Nicholls, 2018; Cupitt, 2018).

1.4.2 | Therapeutic approaches based explicitly on a transformative crisis model

A number of clinicians have developed novel treatment approaches based on experience of helping people in acute crisis (e.g., Calton, Ferriter, Huband, & Spandler, 2008; Mosher, 1999). These often advocate the suspension of psychiatric interventions directed at eliminating the psychosis, in order to allow the transformative process to reach a natural resolution. Sometimes this is only deemed appropriate for a subset of individuals (Ciompi et al., 1992). Milieu therapy is often used, involving home-like settings and compassionate, accepting interpersonal contact (Cole, 2013; Mackler, 2014).

Current the first-person and the professional literature emphasize the importance of supporting the individual to find their own meaning within their experiences: The personal meanings and symbolism in "delusional content" are explored and discussed (Cole, 2013), together with possible connections to traumatic life experiences and existential concerns. The "Open Dialogue" approach (e.g., Bergstrom et al., 2018; Razzaque & Stockmann, 2016) focuses on working with the different and at times conflicting narratives about the crisis within the person's social circle. The aim is to provide a space where a narrative and solution acceptable to all can emerge, rather than the "experts" being expected to provide one.

1.5 | Rationale for the current study

Despite the existence of innovative approaches, mainstream mental health services are still largely based on a medical model (Cooke, Smythe, & Anscombe, 2019), and the ideas outlined above would be new to many clinicians. Clinical psychologists (CPs) have been influential in developing, evaluating, and disseminating new theoretical and therapeutic approaches to psychosis (see, e.g., Bowden, Davis, Nairne, & Shepherd, 2015; Cooke, 2017). Their views on these developments are therefore likely not only to affect their own therapeutic practice but also to be indicative of their potential for wider acceptance. The current study explored CPs' views about transformative models of psychosis.

The research questions were as follows:

- What are CPs' beliefs about the nature of psychosis in general?
- What are CPs' beliefs about "transformative crisis" models in particular?
- How, if at all, do they draw on these approaches in their clinical practice?
- What factors, if any, constrain their practice in this regard?

2 | METHODOLOGY

2.1 | Design

In view of the relatively unexplored nature of the territory, the study utilized an exploratory qualitative methodology, grounded theory (Charmaz, 2006).

2.2 | Participants

The participants were CPs working in a variety of UK National Health Service (NHS) settings, spanning a range of seniority. They had responded to an email circulated to members of the British Psychological Society Division of Clinical Psychology and also, for reasons of theoretical sampling (see below), to the U.K. Spiritual Crisis Network[1] and to a clinical psychology email discussion list focusing on psychosis and spirituality. Volunteers answered a brief questionnaire in order to guide theoretical sampling. Participants were selected to represent a range of service settings and of views on the nature of psychosis. CPs with a stated interest in transformative models were recruited in the first instance, with "negative cases" (i.e., those who subscribed to illness models) being interviewed to test emerging hypotheses. Of 15 respondents, 12 were interviewed. Table 1 summarizes participant characteristics. The confidentiality of participants and their clients has been maintained.

2.3 | Data collection

Semi-structured telephone interviews were conducted by the second author (C. B.) and lasted an average of 1 hour. Topics covered included how participants worked with people experiencing psychosis (e.g., what they saw as the most important aims of psychological therapy, the circumstances under which they would discuss delusional content), the theoretical ideas that informed this work (e.g., views about the causes of psychosis), and any factors that constrained it. Participants were also specifically asked about their views on transformative approaches (e.g., whether they had heard of them and if so what they thought of them).

Interviews were recorded and transcribed. Data collection was continued until theoretical saturation (Charmaz, 2006) was achieved for the main research questions; that is, no new data were emerging that did not fit the emerging theory.

2.4 | Data analysis

The data analysis followed Charmaz' (2006) procedural guidelines for grounded theory. This research method aims to generate theory that is "grounded" in data that have been systematically collected and analysed. It was chosen here because of its utility in exploring undertheorized areas of human experience (Charmaz, 2006). The data were systematically coded in order to identify theoretical constructs that could explain them. Initial coding was conducted line by line and generated new ideas to pursue, leading to a second phase of coding. Focused coding was used to integrate and organize the data into preliminary categories. Axial coding was then used to investigate the properties and dimensions of the categories and to expand on

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[1] A charity and networking organization set up to promote understanding and support of *spiritual crisis*: a term used to denote transformative crisis seen within a transpersonal or spiritual paradigm.

TABLE 1 Details of participants

Participant	Working context	Years since qualification	Age band	Gender
P1	Assertive outreach	2.5	26–35	F
P2	Early intervention in psychosis	11	46–55	F
P3	Acute inpatient unit	16	56–65	F
P4	Assertive outreach	16	36–45	F
P5	Early intervention in psychosis	14	36–45	M
P6	Acute inpatient unit with community follow-up	1	26–35	M
P7	Assertive outreach and community rehabilitation support team	10	36–45	M
P8	Early psychosis: community teams and acute inpatient unit	14	36–45	M
P9	Early intervention and community team	8	36–45	M
P10	Assertive outreach with psychosis, substance misuse, and personality disorder	7	36–45	M
P11	CMHT	36	56–65	M
P12	Assertive outreach	12	36–45	F

Abbreviations: F, female; M, male; P, participant.

the emerging theory. Methods of constant comparison, memo writing, and field notes (Charmaz, 2006) were also used to help in the generation of conceptual insights, and relationships and disparities in the data.

2.5 | Quality assurance

Quality assurance procedures followed Yardley's (2000) guidelines and included participant feedback on the emerging analysis. The process of analysis is inevitably subjective and may have been influenced by the researchers' pre-existing beliefs: Both believe that some psychotic crises can be transformative and are keen to understand, and generate debate in, this area. Through the use of "bracketing" (Willig, 2008), including a reflective diary and interviews about our motivations, expectations, and hopes for the research, the researchers periodically reviewed how our own views might be influencing the emerging model. The reader is invited to take our views into account in evaluating our interpretation and conclusions.

2.6 | Epistemological position

The epistemological position adopted was one of critical realism (Bhaskar, 2013). This stance acknowledges that the statements made by the participants are just that: statements. They are inevitably affected by situational and other factors. However, unlike its more radical cousin social constructionism, critical realism sees participant statements as also containing valuable information about the "real world" (i.e., the phenomena being described) albeit seen through a particular lens. Accordingly, the assumption here is that participant statements do reflect, albeit imperfectly, psychologists' actual beliefs and practices.

3 | RESULTS

The results are presented in four parts, each relating to one of the four research questions. The first describes participants' beliefs about psychosis in general, and the second describes their views about transformative approaches to psychotic crisis. The third describes the ways that these beliefs were reflected in their clinical practice as reported in the interviews, and the fourth describes factors that participants felt constrained their practice. The relationships between these four elements were complex and are explored individually below: For example, although beliefs influenced practice, participants described other factors that also played an important role, for example, the service setting. The main categories that emerged with respect to each question are represented below, and subcategories by bold type in the body of the text. The findings are summarized in Table 2.

3.1 | Beliefs about psychosis in general

3.1.1 | Spectrum of views

As might be expected given the recruitment strategy, participants held a spectrum of views ranging from those who accepted an illness model to those who saw psychotic experiences as inherently purposeful.No participants saw psychosis in purely biological terms (i.e., as a brain problem where the content of beliefs and experiences is largely irrelevant). Two held a **biopsychosocial** view, explaining it as an illness or disorder, albeit with a significant psychological component that explained the context of onset and the particular form of the unusual experiences and beliefs involved. These participants saw psychosis as meaningful in the sense that the content of symptoms could be fruitfully linked with events or situations in the client's life. A second group held a **continuum/trait** view (i.e., schizotypy: Mason & Claridge, 2016) in which psychosis proneness was seen as a trait, often associated with others such as creativity and interpersonal sensitivity. A third

TABLE 2 Clinical psychologists' beliefs about psychosis, effects on clinical practice, and constraining factors

Beliefs about psychosis in general
Spectrum of views: illness/biopsychosocial → continuum/trait → understandable → purposeful
Beliefs about transformative approaches to psychotic crisis
Broad versus specific meanings of "transformative": All crises have transformative potential and psychosis is no different versus Psychosis is inherently purposeful
Distinguishing transformative crisis from other forms of psychosis: Long duration or high distress level is compatible versus incompatible with a transformative approach
Utility of a transformative approach: Service users often find a transformative approach helpful
Aims and methods of therapeutic intervention
Sense-making/formulation: Making sense of experiences reduces anxiety and distress and enables integration and choice
Differing approaches to validation: Normalizing versus actively valuing psychotic experiences
Engaging with the "real" world is important
Reducing the negative impact of experiences and beliefs does not always involve challenging them
Positioning: Psychologists are experts versus Psychologists should adopt a "not knowing" approach
Factors constraining practice
Views about the clinical psychologist role: It is versus It is not appropriate to discuss spiritual issues in therapy
Service context: Medicalized settings reduce opportunities for transformational approaches

Note. Main categories are in italics.

group saw psychotic experiences as **understandable** responses to life situations, particularly trauma. Finally, some went further, believing that the experiences had a particular function, for example, helping to resolve dilemmas or unbearable feelings, and could therefore be seen as **purposeful**:

> *I think people sometimes journey into other worlds to try and find ways to deal with this world*
> (P7).
>
> A number of the latter group believed that psychosis had spiritual aspects or that a "breakdown" often represented a spiritual crisis.

3.2 | Beliefs about transformative approaches to psychotic crisis

Similarly, participants held a range of views about the extent to which psychotic crises are likely to be transformative. Beliefs varied in terms of the way participants understood the term (broad vs. specific meanings of "transformative"), in terms of what might distinguish a transformative crisis from other forms of psychosis, and in terms of the utility of a transformative approach.

3.2.1 | Broad versus specific meanings of "transformative"

Many participants saw psychosis as potentially transformative in a broad sense, in the same way that any crisis could lead to learning and positive change given the right support:

> *It doesn't have to be psychosis, any personal crisis can lead to a transformation, or not*
> (P2).
>
> Others subscribed to a more specific view of the transformative potential of psychosis, seeing the phenomena themselves as inherently purposeful:
>
> *The experience of psychosis would be both the indication of the need for personal development … and partly I guess as a way of doing it in its own right*
> (P5).

Of the latter group, some emphasized the way that trauma can re-emerge into awareness through psychotic experiences, thereby presenting an opportunity to process or resolve it. Some felt that psychosis often represented a spiritual crisis:

> *I got interested in spirituality and psychosis because of doing therapy with people who told me of their breakdown experiences which included mystical experiences*
> (P3).

Many participants stressed that despite its transformative potential, psychosis could also be extremely distressing and destructive:

> *I think it can be very transformative in the long term and in the short term it can be incredibly destructive*
> (P5).

3.2.2 | Distinguishing transformative crisis from other forms of psychosis

Some participants felt that the transformative crisis idea was either only relevant to a minority of their clients or that it might no longer be relevant by the time an individual had experienced significant input from services:

> *There's nobody I work with whose psychosis really fits a spiritual emergency, it's gone beyond that, but there could well have been a spiritual emergency at the onset and there's a strong flavour of spiritual issues in the ongoing psychosis*
> (P10).

Those working in early intervention or acute services were more likely to think that some of their clients' experiences might be understandable as a spiritual crisis. None felt that their service was appropriate in those cases:

> *Is this person having a spiritual crisis … what we have to offer doesn't seem to be … useful*
> (P8).

Some appeared to view experiences as transformative only where the person was not distressed by them:

> *It's … rare that I come across that because the people that I will see are people that are distressed by their psychotic experiences …*
> (P9).

Others had a broader definition:

> *I don't separate out the experiences in a dualistic way, so like, some people have psychosis, some people have spiritual emergence … I'd see all mental health problems as potentially transformative, if people get the right support*
> (P7).

3.2.3 | Utility of a transformative approach

Many participants were drawn to transformative models because they had experienced these as more helpful for clients. They felt that the idea of illness could lead to passivity and hopelessness and that transformative models provide a helpful framework that integrates experiences into people's lives and can reduce anxiety and provide hope.

> *There's a lot of really helpful metaphors in spiritual thinking … that sometimes are less painful ways to look at people's problems*
> (P7).

3.3 | Aims and methods of therapeutic intervention

Even those participants who endorsed a transformative model rarely used specific therapeutic approaches based on it such as those described above. However, it did often impact their general approach: They were more likely than other CPs to offer clients the opportunity to explore and integrate their experiences through making links to biographical factors and looking for lessons inherent in the crisis.

3.3.1 | Sense-making: Containment, explanation, choice, and integration

All participants felt it was important to offer people the opportunity to make sense of their experiences. Many felt that this provided containment and reduced anxiety:

> *If you contextualise it for people it can reduce their distress, it's a way of normalising or making sense of it for them so they've got a narrative of it*
> (P5).

Many, including those who were comfortable with the idea of psychosis as an illness, created a formulation with the person, linking biographical information to the content of unusual beliefs in order to explain how the belief arose:

> *A Tony Morrison or Philippa Garety model of psychosis, that somehow your early experience leads you to have unusual views about yourself and the world, and that you interpret things within the context of that*
> (P2).

Those who saw psychosis as transformative (in either a broad or specific sense) saw therapy as an opportunity to reflect, to discover any links between life events and the content of the psychosis, and to clarify hopes and goals.

> *People get onto the treadmill and end up somewhere in life they don't want to be … . But any crisis, any illness, gives you time to reflect on your life, your values and goals, it can be a transforming experience and I would always include that in the therapy*
> (P2).

Participants also felt that making biographical connections helped to position psychotic experiences as products of the past, allowing the person to have more choice over their reactions:

> *If we … notice … where they've come from, [that creates] … a bit of room to reflect, and choose … do something different than just reacting*
> (P8).

Participants who viewed psychosis as purposeful also talked about making links to life experiences. Here, the aim was not only to understand the origin of the experience but also its purpose and to promote integration. They described facilitating engagement with relevant traumatic or emotional issues, exploring the function of the unusual beliefs and looking for other ways of meeting these needs. They also offered people the opportunity to reflect on and learn from their experiences:

> *If you can learn the lessons … —a meaning—you can turn the crisis into something transformative*
> (P7).

Several participants mentioned the importance of appropriate timing and of the therapeutic relationship:

> *It's being very supportive and not trying to undermine beliefs but perhaps if you've got a really good relationship with someone then you can … suggest alternatives*
> (P7).

3.3.2 | Differing approaches to validation

Some participants drew on ideas that provide a normalizing rationale for experiences whilst not validating their content at face value, for example, paranoid experiences as self-protective mechanisms or dissociative experiences as adaptive responses to trauma (see Cupitt, 2018). Others—often but not exclusively those who had themselves had unusual experiences, or ones they viewed as spiritual—had a validating attitude towards anomalies:

> *I'm very interested in those experiences, so probably my interest shows! I tend to go forward at that point because I think often people are desperate to discuss them … and they need attention*
> (P4).

These psychologists were more likely to see the psychotic state as potentially giving rise to novel insights that might help the client move on. They might facilitate direct engagement with experiences in order to explore them more closely and to consider aspects that might be causing difficulties. However, this was held in balance by a focus on the importance of timing (see above) and of engagement with "real world" activities in line with the client's goals.

Many CPs felt that their remit was to address clients' own concerns and would not refer to transformative models unless clients mentioned them first. Others sometimes did and felt that many people welcomed the perspective and benefited from it in terms of self-esteem and hopefulness.

3.3.3 | Engaging with the world

All participants aimed to help people engage with "real world" goals and activities. Some felt that the content of beliefs was often less important than opportunities to pursue real world goals that might help make them less preoccupying.

> *I like to help the person … get … involved in real world things because I think for some … there is a danger that the ordinary world has got little to offer them, and the psychotic world is so much more attractive and there's very little motivation to leave it*
> (P3).

3.3.4 | Reducing the negative impact of experiences and beliefs

Many participants talked about helping people find ways to reduce the negative impact of unusual beliefs or experiences. Some saw this as often more important than addressing them directly. A number highlighted the possibility of working within the client's belief system:

> *I can work with someone who believes their voices are a product of dissociation, or … someone who believes that they are hearing the voice of the devil … . In both cases I'm trying to help people make peace with that experience and increase their power, choice and control*
> (P7).

3.3.5 | Positioning: "Expert" to "not knowing"

The CPs positioned themselves in differing ways in terms of expertise. This was related to their beliefs about psychosis in that the minority who viewed it as illness were more inclined to use a psychoeducational approach, drawing on a standard model to offer the client a possible formulation of their experiences. In comparison, others held an explicitly "not knowing" position (Anderson, 2005) and worked more from the clients' own understanding:

> *I think I'm much less willing to give advice, I'm more interested in facilitating people to make their own decisions … I try very hard to get alongside people and facilitate the process that they go through rather than having a very strong agenda myself about what I think's right for them*
> (P4).

However, even those who espoused a "not knowing" or "nonexpert" position were balancing two concerns: avoiding invalidating the person's experiences and beliefs, whilst also being aware of the distress these were sometimes causing.

Others explained their approach as presenting information and thereby increasing the options available to the client. This was a way of introducing new ideas (including the idea of transformative crisis) without presenting them as the "truth" about the person's experiences.

3.4 | Factors constraining practice

Two factors constrained the extent to which psychologists felt able to draw on transformative crisis models in their work: views about what was appropriate in the role and the service context

3.4.1 | Views about the CP role

Only three of the six participants who believed that a "breakdown" often represented a spiritual crisis drew on this idea in their work with service users. The others avoided conversations about spiritual issues because they felt that this was not within their remit or training.

> *My role is not a religious one*
> (P4).

Where spirituality was important in the psychologist's own life, this sometimes presented a dilemma. Some felt that there could be a role for faith leaders, although they felt that some may lack necessary clinical skills.

3.4.2 | Service context

The service context played a central role in determining the types of interventions offered. All participants who held nonillness models experienced difficulties working within teams where colleagues did not share their perspective. Many felt that the hegemony of the medicalized approach with its idea of "insight," its emphasis on reducing or removing experiences rather than understanding them, and its frequent use of compulsion undermines trust between service users and professionals. They felt that it makes clients less inclined to be honest with workers; that it promotes a more passive attitude; and that clients in acute crisis are often too heavily sedated to engage in therapeutic conversations.

> *The spectre of enforced treatment can affect the psychological therapy*
> (P3).
> I sometimes feel quite restricted by working within this heavily dominated medical model … I sometimes feel I have to be very careful what I say to clients. (P6)

Those who worked in more "open-minded" teams felt less constrained.

4 | DISCUSSION

4.1 | Summary of findings

The analysis elucidated subtle differences in participants' beliefs about the nature of psychosis. No participants saw it as a purely biological problem where the content of experiences is irrelevant. Two held a "biopsychosocial" model, viewing psychosis as an illness with psychosocial elements. Most either held a continuum view (i.e., schizotypy), in which psychosis proneness was also associated with positive attributes such as creativity or sensitivity, or a "fully psychological" view, seeing experiences as meaningful and/or as adaptive responses to events. Many believed that psychosis can be transformative in a broad sense, that is, lead to "post-traumatic growth." Some went further, believing that it can be a purposeful, that is, an attempt, albeit painful and sometimes unsuccessful, to solve problems and grow. Some of this group believed that at least some "psychotic" crises are existential or spiritual experiences that can be profoundly transformative for the person concerned.

Participants' perspectives influenced their therapeutic approach: Those who saw experiences as purposeful were more likely to facilitate direct engagement with them and to address their possible significance and meaning. However, participants' approaches had much in common. All aimed to offer a space where people could discuss and attempt to understand their experiences in the context of their lives and values. All also focused on concrete opportunities to re-engage with life and pursue "real world" goals. Not all those who personally believed that some psychotic experiences may have spiritual content or relevance presented this perspective to clients.

4.2 | Application of transformative models in the NHS context

Many participants reported that in their NHS work, they rarely came across people whose current experiences met their criteria for transformative crisis. The Grofs' (e.g., 2012) model of spiritual emergency would indeed rule out many of the people presenting to services as it specifically excludes, for example, those with "delusional" beliefs. However, others (e.g., Geekie & Read, 2008; Razzaque, 2014) have argued that a crisis can be simultaneously both very distressing and profoundly transformative, even spiritual. It is possible that some CPs may be excluding some who might benefit from the transformative crisis approach.

One difficulty is the service context. Psychologists with an interest in transformative crisis are often working with teams where colleagues do not share this approach. Counteracting the dominant illness narrative demands energy (Cooke et al., 2019) and dilemmas can arise regarding the ethics of introducing conflicting models.

4.3 | New approach or extension of current practice?

Another notable finding was the overlap between CPs who did and did not view psychosis as purposeful, when it came to intervention. Interventions based on the transformative crisis model (validating experiences, working to integrate insights into everyday life) were often integrated with approaches derived from a more traditional psychological approach (making links between psychotic experiences and life circumstances; addressing trauma; and increasing opportunities for engagement with "real world" goals). This suggests that the adoption of a transformative approach does not represent a radical step, but rather an extension of current practice. In this sense, it does not seem crucial to make a "differential diagnosis," that is, spiritual emergence *or* psychosis. Psychologists are already offering clients information and choice about approaches, so information about spiritual crisis could be more widely utilized in this way. Geekie and Read (2008) found that people experiencing psychosis identified existential needs (the search for meaning and the need for spirituality) as the most pressing. They note that "explanations of causality, which may have helped answer the question of *how* the experience came about, did not seem to quell the need to answer the pressing concern of *why* the psychosis occurred, and (what it) implied for the nature of the individual's world" (p. 192). They encourage clinicians to embrace the notion of "essential contestedness": "a shift on the part of clinicians, away from the position of believing that we already *know* what the experience means, to recognizing that we bring one way of understanding psychosis, but that this is but one among many useful and valued ways" (p. 195).

Where people are preoccupied with the spiritual significance of their experience, it would seem helpful to validate this whilst also addressing its distressing or disabling aspects. Unger (2017) argues that services should adopt a "recovery *and* transformation" approach that encompasses both. "Open Dialogue," an approach to psychosis currently undergoing a large-scale U.K. trial (Razzaque & Stockmann, 2016), explicitly bases all therapeutic conversations on the priorities and beliefs of the person concerned and their loved ones. Professionals act as facilitators rather than as experts charged with explaining what is going on (Seikkula & Olson, 2016).

4.4 | Spirituality and the role of psychologists

Many CPs did not feel comfortable engaging with spiritual aspects of their clients' experiences. Some felt that this was not within their remit, although those who themselves had had spiritual experiences were more willing to explore it. Evidence suggests that the presence of someone who feels comfortable with conversations about spirituality can be helpful to individuals in crisis, as long as they do not impose their own views (Clarke, 2010). This raises the question of whether CPs should have some means to develop competency in this area. Alternatively or additionally, faith specialists could be more closely and routinely integrated into services. CPs could also usefully signpost to peer networks and user/survivor run services such as the Hearing Voices Network (www.hearing-voices.org), the Spiritual Crisis Network (www.spiritualcrisisnetwork.uk/), and EmergingProud (https://emergingproud.com; see also Moynihan, 2014), in order to facilitate access to alternative perspectives.

4.5 | Training

None of the CPs said they had received any training in transformative models of psychosis or their associated interventions. It is also striking that some of the participants' views of transformative crisis used the presence of distress or de-adaptation as exclusion criteria. This suggests that training could usefully include more explicit presentation of transformative models.

4.6 | Limitations and future research

This study has examined CPs' accounts of their work, considering them in the light of extant data and first-person accounts. However, it cannot answer questions about the relative value or efficacy of the therapeutic interventions that the CPs describe. Future research could usefully involve case studies based on information from both the therapist and the client on the aims, process, and benefits of their work together (see McLeod, 2010).

This study only addressed NHS settings. Future research could examine the potential application of these approaches in different settings, for example, nonmedical approaches to acute crisis (Cooke, McNicholas & Rose, forthcoming). In such settings, the possibilities for offering help may be less constrained, and it could be possible to assess whether the transformative potential of crises can be realized, at least for some.

This was a small, qualitative study that specifically recruited CPs with an awareness of transformative models and did not aim for generalizability. It would be useful to carry out a wider survey in order to establish the representativeness of the current findings. Research based on direct observation of therapeutic practice would also be useful.

Despite its limitations, this study suggests that at least some U.K. CPs are adapting their work to encompass developing theory and practice in the area of transformative approaches to psychotic crisis. They view this as an extension of, rather than a departure from, conventional psychological approaches. It will be interesting to follow the development of these ideas and their practical application in the United Kingdom and internationally.

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CONFLICT OF INTEREST

None.

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PEER REVIEW

Stigma: a linguistic analysis of the UK red-top tabloids press' representation of schizophrenia

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Abstract

Aims: Media representations of mental health problems may influence readers' understanding of, and attitude towards, people who have received psychiatric diagnoses. Negative beliefs and attitudes may then lead to discriminatory behaviour, which is understood as stigma. This study explored the language used in popular national newspapers when writing about schizophrenia and considered how this may have contributed to the processes of stigmatisation towards people with this diagnosis.

Methods: Using corpus linguistic methods, a sample of newspaper articles over a 24-month period that mentioned the word 'schizophrenia' was compared with a similar sample of articles about diabetes. This enabled a theory-driven exploration of linguistic characteristics to explore stigmatising messages, while supported by statistical tests (log-likelihood) to compare the data sets and identify words with a high relative frequency.

Results: Analysis of the 'schizophrenia' data set identified that overtly stigmatising language (e.g. 'schizo') was relatively infrequent, but that there was frequent use of linguistic signatures of violence. Articles frequently used graphic language referring to acts of violence, descriptions of violent acts, implements used in violence, identity labels and exemplars of well-known individuals who had committed violent acts. The word 'schizophrenic' was used with a high frequency ($n = 108$) and most commonly to name individuals who had committed acts of violence.

Discussion: The study suggests that while the press has largely avoided the use of words that press guidance has steered them away from (e.g. 'schizo' and 'psycho'), they still use a range of graphic language to present people with a diagnosis of schizophrenia as frighteningly 'other' and as prone to violence. This repetition of negative stereotypical messages may well contribute to the processes of stigmatisation many people who experience psychosis have to contend with.

INTRODUCTION

Many people who receive a psychiatric diagnosis experience reduced life opportunities as a result of prejudice and discrimination.[1] These include opportunities for work,[2] housing,[3] access to financial resources[4] and optimal healthcare.[5] Some people find that the diagnosis leads to distancing behaviours from friends and family,[6] which in turn can make it harder to manage the challenges life presents. Realistic fears of prejudice and discrimination can also prevent people seeking support when they experience distress.[7] All of this has been implicated in the pattern of reduced life expectancy for people with a diagnosis of schizophrenia.[8,9]

In the context of mental healthcare, prejudice and discrimination are often referred to as 'stigma'. This term has been criticised for individualising and medicalising the issue and at times ignoring issues of power and oppression.[10,11] However, the term is widely used in the literature that we review here. As such, stigma is understood to include the processes of labelling human differences,[12] of negative stereotypes being applied to understand groups of people,[12] who as a result are experienced as

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different from 'us'[12] and typically this is linked with negative affective responses.[13] It also refers to behaviours that lead to discrimination and loss of life opportunities, such as those noted above, which require the exercise of power to be enacted.[14]

Stereotypes play an important role in the process of stigmatisation and there is evidence that the press' representation of mental health may contribute to negative attitudes in the readers. Research has demonstrated that reading news stories about violence committed by someone identified as having a diagnosis of a mental illness is associated with increased negative attitudes towards all people with such diagnoses.[15–17] While these studies are only able to identify an immediate effect, rather than a lasting influence, they lend support to the view that the press representations do influence the beliefs and attitudes of their readers.

Stigma may also become internalised by those who receive a diagnosis. This is referred to as self-stigma[1] and this is associated with lowered self-esteem and self-efficacy.[18] Media stereotypes appear to have a direct effect in this area as well. Campaigner Jonny Benjamin, for example, described the desolation he experienced on receiving the diagnosis of schizophrenia: 'All I knew was what I read in the papers, that people with schizophrenia are violent and incapable of recovery'.[19]

In order to try and improve coverage, guidance has been published for the media in general[20] and specifically for the press.[21] These have been supported by awards for practices that promote anti-stigmatising beliefs and attitudes[22] and by training for people working in the media.[23] Language choice is understood to play an important part in the influence of the media on the publics' understanding of mental health problems, evoking negative emotional responses such as fear and potentially constructing spoilt identities.[24]

Research into how the press has written about mental health has highlighted a pattern of using pejorative language.[25,26] This has included the use of words such as *monster* and *lunatic*,[27] *maniac* and *psycho*,[28] *deranged* and *schizo*[29] and broadly sensationalistic language.[30] In the UK, the red-top tabloid press has been found to use this type of language more commonly than other sectors of the press[31,32] and consequently this has raised concern about how this group of newspapers write about mental health, particularly given their high readership.[33] Collectively, this type of language is understood to contribute to readers constructing understandings about people with mental health problems as *other*, and a potential threat.[34]

In their seminal paper about the processes of stigmatisation, Link and Phelan[14] comment that the degree to which a label shapes identities of the individuals within the group is reflected in language that refers to individuals simply by their diagnosis. This line of thought has prompted enquiry into how the word 'schizophrenic' has been used in the press to name an individual, which Clement and Foster[31] refer to as using the word as an 'equator descriptor'. Findings in the UK suggest that it has been common across all press outputs but particularly common in articles describing violent acts.[31]

This study explored the linguistic characteristics of the red-top tabloids' representation of 'schizophrenia'. The research question was as follows: how may the linguistic characteristics of the red-top tabloids' representation of schizophrenia contribute to the processes of stigmatisation?

METHOD

The use of sensationalist language and equator descriptors in UK red-top tabloid newspapers were explored using corpus linguistic methods. Corpus linguistics is a common approach within linguistic analysis[35] but is underutilised in mental health research. Research into the language used to describe mental health problems has typically relied on a priori decisions about which words to identify and count within the data set. Corpus linguistic software uses an inductive approach to explore linguistic patterns without prior assumptions and more efficiently than would be possible by hand.[36] This study used the computer software, AntConc,[37] to support the analysis as this has been found to be reliable[38] and is free to download.

Two types of analysis are commonly used in corpus linguistics. The first is *concordance analysis* in which each line of text is presented that contains a particular word, selected by the researcher. This is referred to as the *key word in context*[39] and enables an efficient scanning of word usage.[40] Each example can be explored further if the meaning is unclear from the one line. The second type of analysis is *keyness analysis* where the data set under enquiry is compared with a comparator data set in order to identify words that are used with greater or lesser proportional frequency.[41] Statistical analysis is used to establish the likelihood that such a difference would occur by chance. The words are rank ordered by their statistical value and the researcher then makes theoretically informed decisions about which words characterise the data set under review. In this research, for example, the theoretical concept of stigma drove the decision about the identification of words that may contribute to stigmatising beliefs and attitudes.

The data set of newspaper articles was constructed using the LexisNexis database, which is the industry standard for newspaper research in the UK and the US.[41] The database allows for a search of articles within all the UK red-top tabloid newspapers (*The Sun, The Daily Mirror, The Star, The People, The Sunday Sun, The Mirror on Sunday, The Star on Sunday*), filtered by all articles containing a key word and by a chosen time period. For this study, all articles within this group of papers that used either the word *schizophrenia* or *schizophrenic* were identified throughout a 24-month time period from 1 April 2016 to 31 March 2018. All of these articles were copied into a Word document and half were randomly selected creating a data set of 210 articles for analysis. To support the keyness analysis, a data set was constructed of articles within the same group of newspapers and during the same time period, but filtered by the inclusion of the words *diabetes* or *diabetic*. This comparator data set was constructed as it would share the same

Table 1

Linguistic signatures of violence in 'schizophrenia' articles, arranged by categories and ranked by log-likelihood value (G_2)

Acts of violence			Description of acts			Implements of violence			Identity labels			Exemplars		
Frequency	G_2	Word	Frequency	G_2	Word	Frequency	G_2	Word	Frequency	G_2	Word	Frequency	G_2	Word
74	92.81	Murder	17	15.13	Violent	17	15.13	Hammer	105	129.19	Schizophrenic	153	191.91	Sutcliffe
59	74.00	Stabbed	14	11.74	Horror	7	8.78	Screwdriver	88	74.92	Killer	128	160.55	Brady
65	49.57	Killed	9	11.29	Brutal	11	8.44	Axe	12	15.05	Attacker	63	79.02	Hindley
38	47.66	Murders	13	10.63	Horrific	5	6.27	Gun	11	13.80	Killers	28	35.12	Huntley
30	37.63	Attacked	7	8.78	Chilling	4	5.02	Knives	18	12.63	Monster	11	13.80	Erskine
105	28.98	Death	6	7.53	Crazed				10	7.37	Murderer	5	6.27	Bamber
22	27.60	Killings	6	7.53	Frenzied				4	5.02	Murderers	5	6.27	Shipman
11	13.80	Knifed	4	5.02	Gruesome				4	5.02	Rapist	4	5.02	Breivik
10	12.54	Strangled							1	1.25	Psychos			
5	6.27	Axed							1	1.25	Schizo			
5	6.27	Bludgeoned							4	0.43	Beast			
5	6.27	Hacked							2	0.22	Psycho			
4	5.02	Beheading												
4	5.02	Raped												
7	4.28	Slashed												

Table 2

The categories and frequencies of use of the word 'schizophrenic'

	Formal (violence)	Formal (not violence)	Fictional	Informal	Metaphorical
No. of instances	58	22	5	13	7

qualities of time period and newspapers and would only be differentiated by the difference of physical health rather than psychiatric diagnosis. Diabetes was chosen as it had proven to be a relevant comparator diagnosis in previous research into press representations of mental illness.[42]

The log-likelihood test was used to identify words with a proportionally high frequency in the 'schizophrenia' data set compared against the diabetes data set. Log-likelihood is more conservative than alternative statistical tests, such as chi-square, when analysing whether words with low frequency are used proportionally more frequently in one data set than the other, beyond the differences expected by chance.[41] Words with a statistical value greater than 3.84 are regarded as having a significant proportional high frequency of use, based on an alpha threshold of $p < .05$.[43] All words in the 'schizophrenia' data set with a statistical value greater than 3.84 were scanned to identify features that may contribute to stigmatising messages. Additionally, all words that press guidance advises not to use, e.g. 'psycho' were identified, irrespective of their statistical value.

RESULTS

Stigmatising descriptors

From the list of words with a statistical value greater than 3.84, 44 words were identified as contributing to stigmatising constructions of schizophrenia and an additional 4 words were identified that were contrary to press guidance (*schizo, psycho, psychos, beast*). The striking characteristic of the 'schizophrenia' data set was the number of violence-related words present; a typical example was as follows: 'The schizophrenic slashed five others before cops Tazered him' .[44] The words fell into five categories: acts of violence (e.g. murder), descriptions of acts (e.g. violent), implements of violence (e.g. hammer), identity labels (e.g. schizophrenic) and exemplars (e.g. Sutcliffe). The findings illustrate the repeated use of graphic language in this group of newspapers over a 24-month period in relation to people with a diagnosis of schizophrenia. Table 1 shows both the frequency with which the words were used and their proportional frequency in the 'schizophrenia' than in the 'diabetes' data set, by means of the log-likelihood value (G_2). The exemplars identified are culturally specific references to individuals who have notoriety in the UK and have committed homicide; these are included as they are regarded as a mechanism within the press to heighten the affective response of fear in readers.[28]

'Schizophrenic' as an equator descriptor

The word *schizophrenic* is sometimes used as a shorthand for referring to people with a diagnosis of schizophrenia. Press guidance advises against using this term, suggesting it encourages readers to reduce the identity of individuals to a diagnostic label.[14,21] Concordance analysis of the 'schizophrenia' data set identified that the word *schizophrenic* was used 105 times. The word was present in 101 articles, indicating that in 48% of the articles in the data set, the word 'schizophrenic' was used, and closer analysis identified its use fell into five discrete categories, represented in Table 2.

There were 80 references to people with a formal diagnosis of schizophrenia. In light of the findings reported above, these examples were separated into those that were linked to violence and those that were not, indicating that 58 instances were related to violence and 22 were not related to violence. There were five references to fictional characters in films, books or television. There is evidence of over-representation of mental health in fictionalised accounts of violence, such as horror movies,[45] which is a source of concern about the broader cultural representation of mental health. However, these references to fictional characters were counted separately, as it is understood that in the context of press outputs readers would treat them differently from accounts relating to real people.[46] There were 13 instances of what we termed 'informal' usage, that is, where it is clear that the term does not refer to an 'official' or formal diagnosis. The most common news story referred to the US President Donald Trump's former Communications Officer Anthony Scaramucci. One typical example, from the *Daily Mirror*,[47] stated, 'Kelly takes over his position from Reince Priebus who was sacked 24 hours after communications head Anthony Scaramucci branded him a "f*****g paranoid schizophrenic"'. Finally, there were seven instances of 'metaphorical' use of the term schizophrenic to denote things or people being split or contradictory; examples included 'Jurgen Klopp's schizophrenic side'.[48] Here, the tone was not strongly negative with regard to implications of violence, but usually presented the state of affairs as leading to negative consequences.

DISCUSSION

The striking feature of the study findings is the repetition and graphic nature of the language of violence used in the 'schizophrenia' data set. To state simply that the articles were characterised by graphic language misses the impact of the use of such emotive words. The repetition of people being 'stabbed', 'strangled' and 'beheaded' with a 'hammer', 'screwdriver' or 'axe' is designed to induce a response of fear in readers.[21] These affective responses are central to people developing prejudicial attitudes, as stereotypical beliefs about dangerousness become fused with emotional reactions to those beliefs.[13] In this context, the newspapers appear to use, almost casually, language that reduces a person's identity to one dominated by the act of violence, for example, 'killer' or 'monster'.

The drive for the press to avoid the use of the word 'schizophrenic' as an equator descriptor appears to have had little effect: in our sample, it was frequently used ($n = 105$), particularly in relation to people who have committed acts of violence ($n = 58$). The review of the use of the word 'schizophrenic' indicated that it was used almost three times more often in relation to real people who had committed acts of violence than those who had not. The interpretation of a text will vary from individual to individual, influenced by their life experiences and social context.[49] However, the results suggest that when the language in articles encouraged readers to view the person as 'other' – for example, due to their 'crazed' violence – it was more likely to also reduce their identity to their diagnosis (i.e. by referring to individuals as 'schizophrenics'). This reduction of someone to a diagnosis, combined with linking that diagnosis with violence, is likely to reinforce the process of 'othering' whereby readers come to see certain people as insurmountably different and abnormal.[34] This may be particularly significant, as establishing empathetic links with people with a diagnosis of mental illness is important in countering negative attitudes and beliefs.[50]

Previous research in this field has tended to focus on the identification of pre-established lists of words that are considered to be stigmatising, such as *psycho*[28] and *schizo*.[29] Such words were used relatively infrequently. On one hand, this could be seen as evidence of a positive move within the press industry, and perhaps that campaigns to encourage journalists to avoid these terms have had some effect. However, by broadening the focus beyond these predetermined words to analyse the characteristics of the data set, the present study has revealed a pattern of linguistic signatures of violence in the articles. Link and Phelan[14] caution that the pervasive nature of stigmatisation means that attempts to address one discrete area may well mean that alternative methods of stigmatisation are employed. The findings from this study support that view and raise concerns that while the press may respond positively to a checklist of terms to avoid, it continues to draw on language that constructs people with a diagnosis of schizophrenia as violent.

The use of corpus linguistics has proven to be a useful method to analysis beyond a priori lists of words that the press should avoid, or use with caution, to a wider survey of the language used in construction of identities. The findings are consistent with those from other types of research in the field about the repetition of themes of violence in mental health news[51] but also provide new data about the manner in which the language of violence is employed. The results suggest that this approach could be a useful addition to the methods more commonly used in this area of stigma research such as content analysis.[45] Furthermore, as newspaper readership numbers have declined and social media has increasingly become a source of news information,[52] there will be new challenges to managing the potentially large data sets associated with these new platforms. Corpus linguistics has been used to analyse very large social media data sets,[53] and may well be a useful approach to examine representations of mental health in platforms with a global reach, such as Twitter.

CONCLUSION

Stigma towards people with a diagnosis of mental illness is a global public health issue that impacts negatively on a substantial number of people across a range of life areas.[54] The press is just one element of this complex process. However, this study suggests that language used in this group of widely read newspapers may contribute to negative views of those diagnosed with schizophrenia, and particularly to a perceived association with violence. The findings suggest that it may be misguided to focus only on encouraging journalists to avoid using pejorative terms such as *psycho* and *schizo*. While this is important, the results suggest that newspapers frequently use words which are linguistic signatures of violence. This repeated use of the language of violence, together with the use of the word *schizophrenic* to reduce the individual to a diagnostic label, is of great concern. Such negative coverage in popular newspapers may well contribute to the processes of stigmatisation towards those who experience psychosis – many of whom have already experienced significant disadvantage, prejudice and discrimination.[18]

CONFLICT OF INTEREST

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

ETHICAL APPROVAL

The research is based on publicly available literature and does not require any declaration.

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Conflict, compromise and collusion: dilemmas for psychosocially-oriented practitioners in the mental health system

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ABSTRACT
The nature and causes of mental health problems are contested. The dominant approach in services views them as "illnesses like any other". The structure, legislative base and practices of mainstream mental health services are largely predicated on this idea, known variously as the medical, illness, disease or diagnostic model. By contrast, psychosocial theories highlight the role of the events and circumstances of peoples' lives. The tension between these two approaches can lead to challenges and dilemmas for psychosocially oriented practitioners. Clinical psychologists participated in interviews and a focus group about these challenges and how they managed them. A grounded theory was constructed which suggested that their responses took three forms: openly "dissenting" (*conflict*), strategically "stepping into" the medical model (*compromise*), or inadvertently "slipping" into it (*colluding*). Strategies for managing the challenges included focusing on clients; foregrounding clients' contexts and understandings; holding the tension between "expert" and "not-knowing" approaches; using ordinary language; forging robust working relationships; being mindful of difference and of constraints on colleagues; recognising one's power and ability to influence; self-care and work/life balance; taking encouragement from small changes; consolidating a personal philosophy; mutual support and solidarity; drawing on scholarship and finally engaging in activism outside work.

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Introduction

There is considerable debate about the nature and causes of psychosis and other "mental health problems", and therefore about the best way/s to intervene (Cooke, 2017a; Johnstone et al., 2018). The two most widely adopted frameworks are said to be the *medical model* and the *psychosocial model* (British Psychological Society (BPS), 2007). There have also been attempts to reconcile the two in the form of the "*biopsychosocial*" approach (e.g. Frances, 2014; Murray, 2017).

The medical model

Definitions vary of the term "medical model" and of related terms such as illness, disease or diagnostic model. Here the term is used to denote the idea that mental health problems are best understood as "illnesses like any other" (Pescosolido et al., 2010). Aetiology is often explained primarily in terms of an underlying problem with the brain, perhaps a genetic abnormality or

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chemical imbalance (Read, Mosher, & Bentall, 2004). Psychiatrists assign diagnoses by classifying into groups of "symptoms" the person's observed behaviour and/or their descriptions of their experiences (Johnstone, 2014). Medical interventions (mainly medication) are generally seen as the core treatments, with psychosocial interventions typically viewed as adjuncts (e.g. Craddock et al., 2008).

Despite its dominance, the medical model has been subject to sustained critique (e.g. Bentall, 2010; Cooke & Kinderman, 2017; Moncrieff, 2013). Critics highlight scientific, practical and ethical issues: real-life problems rarely divide up in the ways that the categories suggest; no "biomarkers" (evidence of biological causation) have been found (Insel, 2009); disorders are voted into and out of existence by committees (i.e. the panels determining what is included in the standard manuals), and treatment often proceeds relatively independent of diagnosis (Kamens, 2013). Some authors suggest that the approach can lead to "myopia" with respect to the role of life circumstances (McGowan & Cooke, 2013). Others highlight the social and psychological impact of being labelled "mentally ill" (British Psychological Society (BPS), 2011). Note that these are critiques of the *theory* and its associated practices rather than of the medical or psychiatric *profession*: indeed, some of the most prominent critics have been psychiatrists (e.g. Moncrieff, 2013; Mosher, 1998).

The psychosocial model

The psychosocial model has been defined as a framework that removes biology from the position of privilege in favour of a focus on the relational, interpersonal and social contexts of distress (Boyle, 2006). Behaviours and experiences – no matter how bizarre or disturbing – are thought of as understandable and meaningful, if sometimes problematic, responses to events and circumstances (Beresford, Perring, Nettle, & Wallcraft, 2016; Tew, 2011). As such it is inevitably challenging to the status quo.

Dominant models within conventional western mental health systems

Despite the attempts at integration outlined above, the medical model arguably remains dominant within most Western mental health systems and is reflected in both their structure – with services delivered from hospitals and clinics – and their legislative base (Kinderman, 2014). For many, physical treatments such as medication or electro-convulsive therapy remain the only ones on offer (Beresford et al., 2016; Read, Harrop, Geekie, & Renton, 2018). A number of reasons have been suggested for the model's continued dominance including the vested interests at stake, the influence of the pharmaceutical industry and social expectations of "a pill for every ill" (Rogers & Pilgrim, 2014).

Clinical psychology and the medical model

Differences of view about the nature and causes of mental health problems are a source of tension and can be obstacles to multidisciplinary working (BPS, 2007). Whilst some clinical psychologists see little conflict between psychosocial and medical approaches (e.g. Congdon, 2007), there is also a strong tradition of critique and promotion of psychosocial alternatives (see e.g. BPS, 2011).

Senior psychologists have urged their colleagues not to "jump ship" from psychological to medical explanations (Harper, Cromby, Reavey, Cooke, & Anderson, 2007) and to resist the pressure to adopt medical discourse and practices (Kinderman, 2014). Psychologists are exhorted to engage in "constructive conflict" with colleagues in order to acknowledge and address theoretical differences (BPS, 2007, p. 21) and to offer an authoritative and constructive counter-balance to the medical model.

However, little is known about how clinical psychologists, or indeed other psychosocially oriented practitioners, experience working in a system dominated by the medical model, or what the implications of engaging in "constructive conflict" could be (Sidley, 2015).

Johnstone (1993, 2001) describes feeling silenced when working in a multidisciplinary team, and experiencing isolation and a gradual corrosion of her energy and enthusiasm. Newnes (cited in Newnes, Holmes, & Dunn, 2001, p. 6) states *"The process is tiring, not least due to the energy taken up in defending against feeling disliked and waking in the night overwhelmed with paranoid anxiety…"*

Boyle (2002) suggests that in such circumstances some workers reluctantly start to use medicalised concepts and language. Others (Johnstone, 1993, 2001) search for escape routes, for example moving into management, only working with individual clients, or leaving the mental health system altogether. Gelsthorpe (1997, 1999, 2007) encourages psychologists to remain engaged in critical debate and to channel uncomfortable feelings into constructive action to improve services.

The extant literature in this area consists largely of personal accounts such as those mentioned above (see also Freeth, 2007; Frost, 2012; Sidley, 2015). There has been little systematic empirical or theoretical examination. Moreover, much of the literature relates to problems working in "the system" in general rather than to those specifically associated with its guiding ideas. This is perhaps a surprising omission given the centrality of this issue not only for many workers but also for many service users (Beresford et al., 2016) and is one that the current study aims to address. Clinical psychologists were chosen as an indicative example but the issues are likely to be similar for other psychosocially oriented practitioners.

The main research questions were as follows:

- How do clinical psychologists who are critical of the medical model experience working in teams where it is dominant?
- How do they experience challenging it in their teams?
- What are the associated personal and professional challenges?
- How do they respond to these challenges and what enables them to remain committed to working in the mental health system?

Method

The Canterbury Christ Church University Ethics Committee granted approval for the research. The study was carried out in accordance with university and BPS (2007) guidelines. Data collection and analysis followed standard Grounded Theory procedures (Charmaz, 2006). This research method aims to generate theory which is "grounded" in data that has been systematically collected and analysed. It was chosen here because of its utility in exploring under-theorised areas of human experience (Charmaz, 2006).

Participants and data collection

Nineteen UK clinical psychologists took part: nine in individual semi-structured interviews and a further ten in a focus group. Interviewees were recruited via emails circulated within the Psychosis and Complex Mental Health Faculty of the BPS Division of Clinical Psychology and also to the UK Community Psychology Listserve (https://www.jiscmail.ac.uk/cgi-bin/webadmin?A0=COMMUNITYPSYCHUK). Inclusion criteria included having worked in a mainstream mental health team for over two years, and defining oneself as critical of the medical model (see Smythe, 2009).

Since participants were drawn from throughout the UK, interviews were conducted by telephone. Table 1 presents details of participants.

Interview participants were asked to describe:

- How the medical model manifested in their workplace.
- Challenges and dilemmas to which this gave rise, and
- Any strategies they used to manage these.

Table 1. Details of interview participants.

Pseudonym	Work setting	Years qualified
Jennifer	*Acute in-patient service*	*13 years*
Anthony	*Acute in-patient service*	*10 years*
Natasha	*Treatment and recovery service*	*3 years*
Hamish	*Early intervention service*	*9 years*
Patrick	*Community mental health team*	*5 years*
Klaus	*National treatment centre*	*4 years*
Helen	*Community mental health team*	*20 years*
Kristy	*Recovery service*	*7 years*
David	*Crisis team*	*4 years*

A further ten clinical psychologists took part in a focus group, with the aim of triangulating data sources and possibly generating richer data (O'Donoghue & Punch, 2003). Participants in the latter were attendees at a regular PCMH Faculty meeting, and therefore a less self-selected group than the individual interviewees. Members were drawn from across the UK: all worked as clinical psychologists mainstream mental health settings. A questionnaire established that all fitted the criteria.

Focus group participants were presented with passages of text illustrating emerging categories from the interviews. Members were asked to discuss their interpretation of the passages and the extent to which they felt these reflected relevant issues.

Analysis

Grounded Theory requires that categories emerge out of the data rather than reflecting prior researcher assumptions or expectations (Charmaz, 2006). Sampling was continued until theoretical saturation was achieved in relation to the majority of categories, i.e. no new data was emerging that did not fit one or other (Bowen, 2008). The analysis was undertaken primarily by the second author (WS) and followed Charmaz' (2006) guidelines. Emerging themes and codes, together with the developing theory were discussed with the other authors, who also coded part of one transcript independently for comparison purposes. Quality assurance measures followed Yardley's (2000) guidelines and included a bracketing interview (Rolls & Relf, 2006), memos and a research diary as well as the cross-checking of coding between researchers. It is acknowledged that there is always an inevitable element of subjectivity in the analysis: our prior assumptions will have played a role. The authors are ourselves critical of the medical model and have struggled with similar dilemmas to those described by participants: the reader is invited to take this into account in evaluating our interpretation and conclusions.

Epistemological position

The epistemological position adopted was one of critical realism (Bhaskar, 2013; Charmaz, 2006; Willig, 2016). This stance – consonant with the more general stance of the authors – acknowledges that participant statements are just that – statements – and as such are affected by social processes such as desirability responding. However, unlike its more radical cousin social constructionism, critical realism sees these statements as also containing valuable information about the "real world" albeit seen though a particular lens. Accordingly, the assumption here is that participant statements do reflect, albeit imperfectly, participants' actual experiences, views, feelings and actions.

Results and discussion

Results and discussion are presented together for brevity and clarity.

Summary

Participants described their **discomfort** at the domination of the mental health system by the medical model, which they saw as hegemonic and embedded in team practices and assumptions. They felt the focus was predominantly on individual deficits rather than on people's context and circumstances, and that diagnoses obscured the impact of life events. They worried that many practices replicate wider power imbalances and earlier traumas and abuses that people have suffered. They felt that teams are often blind to the shortcomings of treatments. Reflecting on the reasons that the system remains "stuck" in the medical model ("**making sense"**), they felt that organisational structures and practices are hard to change, and a "language barrier" makes it hard to articulate and share alternatives to medical discourse. They felt that in the face of complexity and extreme distress, teams welcome the (false) "safe certainty" that the medical model appears to offer. They also suspected that its popularity with psychiatrists was partly related to a fear of losing power and influence.

There were three main ways in which psychologists responded to the hegemony of the medical framework. The first was open dissent ("**conflict**"). The second was strategically "stepping in" to the model ("**compromise**"). Thirdly, some participants described at times inadvertently slipping into "**colluding**" with the medical model. Finally, participants described the **strategies** that enabled them to remain working in the system in a way that they hoped was helpful. These strategies fell into five categories: *client-related, team-related, self-related, support-related* and *political*. They are described below.

Figure 1 is a visual representation of the grounded theory model that was developed.

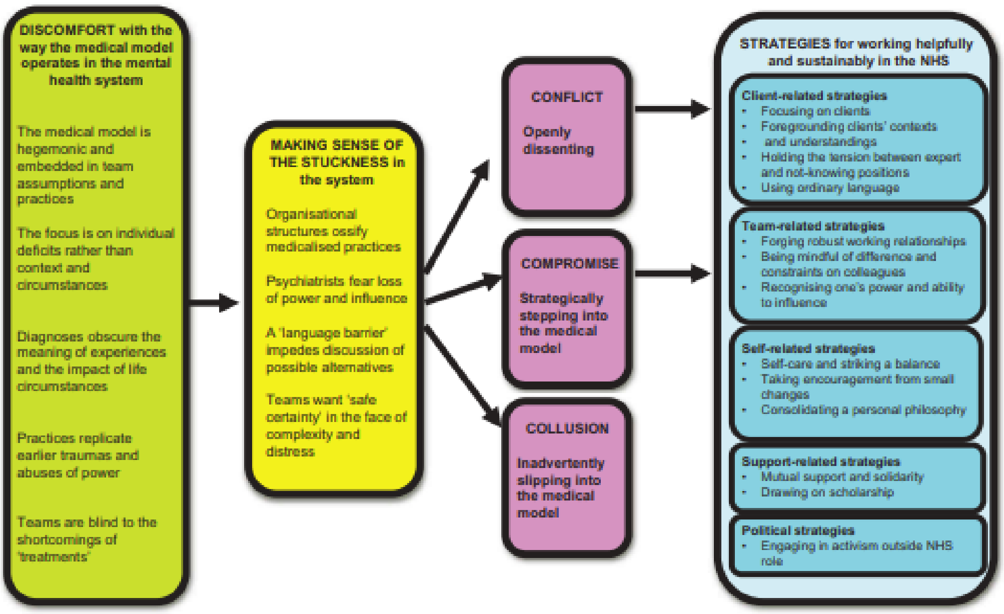

Figure 1. A grounded theory model illustrating how clinical psychologists who are critical of the medical model describe their experiences and practice in UK NHS Adult Mental Health Services.

Discomfort with the effects of the medical model

Participants expressed frustration at the hegemony of the medical model and the way it was deeply embedded in their teams' thinking and practices.

> "In a CMHT the basic assumptions that most people make… kind of fall back on the illness model…you don't have to scratch the surface that much before you get down to that."
>
> (Patrick)
>
> "I've felt frustrations and anger and general disgruntlement with a model that it appears very difficult to avoid in secondary care".
>
> (Hamish)

Teams were also seen as focusing on putative individual deficits rather than on the often very difficult events and circumstances of people's lives. Participants felt that discussions focused on diagnosis and medication, and often failed to consider the person's own views or indeed the possible impact of the diagnosis and treatment itself.

> *"We had a big discussion this morning about whether someone had delusional disorder or schizophrenia…I was saying …isn't the point really (laugh) what effect this is having on his life?"* (Helen)

Many participants described discomfort with the way diagnostic labels were used within their teams:

> *"For me, diagnostic labels…are often used pejoratively and dismissively, like, 'they are just a bit PD [personality disorder]' Sometimes language can be used to keep people in their place…"* (David)

Several participants expressed discomfort at the way that certain practices replicated aspects of previous traumas that the person had experienced:

> *"Some of the practices that we do here… are actually recreating some of the abusive experiences that she had as a child…"* (Jennifer)

Some participants were frustrated that their teams sometimes appeared not to notice – or to turn a blind eye to – the possible negative impacts of particular interventions:

> *"A couple of my clients died while I was there and they had been made to take [name of drug] which …has potentially fatal side effects. And people just totally failed to see, or didn't want to see, the possible connection."* (Kirsty)

Making sense of how things work in the system

Many participants described feeling discouraged or angry because of pressure to work in a way that conflicted with their values and training:

> *"You can sometimes end up feeling angry and annoyed with constantly coming up against the medical model when really – that's just not how I think, or how I'm paid to think…"* (David)

This led them to reflect on possible reasons for the system's resistance to change. Some felt that psychiatrists held on to the medical model because they feared losing power and influence should the system become more psychosocially oriented. Many also felt that organisational structures ossified medicalised practices:

> *"The* (Government) *Department of Health are asking for targets in terms of diagnosis, there are a lot of external pressures…to…use that way of thinking about people…"* (Jennifer)

Participants felt that another impediment to change was a "language barrier" (David) that made it hard to articulate possible alternatives in a way that could be heard.

> *"They can be a bit puzzled… I use terms like 'distress' and 'unusual experiences' rather than mental illness, and people are saying…no one's going to know what you're talking about if we put that in our professional policy…"* (Kirsty)

The idea of a language barrier is consistent with Boyle's (2002) assertion that medicalised discourses have become so dominant that it is hard to find other ways of talking about distress.

Participants felt that one reason that the medical model remains so dominant is that it provides workers with a reassuring sense of certainty. As Coles, Diamond, and Keenan (2013) put it: "A societal understanding may leave (workers) feeling unable to help, whereas biomedical understandings provide an alluringly simple framework and cure" (p. 113). This idea echoes Mason's (1993) concept of "safe certainty". Mason suggests that unhelpful interactions can be set up when professionals worry that they ought to have an expert "fix" for complex problems.

Constantly being faced with, and trying to stay attuned to extreme distress also understandably stirs up difficult emotions. Participants felt that the medical framework enabled workers to feel they were offering something useful, whilst not requiring emotional involvement with people's distress. It was therefore a comfort.

> *"If you start to really listen to people's distress and… to what it means, then it's just horrible.(…) It's just so much easier to say, wow, you're just psychotic, take some more pills…"* (Kirsty)

There are also echoes of Menzies-Lyth's (1988) suggestion that for staff involved in difficult healthcare work, working practices and organisational structures can act as a protection against anxiety. This can make practices difficult to change even when they have significant shortcomings.

Finally, the concept of "emotional labour" may be relevant (see e.g. Edward, Hercelinskyj, & Giandinoto, 2017). Workers may have unconsciously been drawing on the medical model "story" (i.e. that the mechanism of change is biological rather than being rooted in human relationships) in order to protect themselves from emotional exhaustion.

Having attempted to understand the continuing hold of the medical model, participants were left with the dilemma of how to respond. Responses ranged from open dissent (and sometimes conflict) through various types of compromise, to finding themselves slipping into what felt like collusion. These three types of response will now be addressed in turn.

Conflict: openly dissenting

One strategy was simply to offer a dissenting perspective. If offered in a collegial way, this could often be successful:

> *"Where I am at the moment generally it feels that I am listened to and the alternative is valued"* (Helen)

Others, however said that their attempts were often greeted with ambivalence, ignored or even dismissed:

> *"It's isolating, and my God it gets frustrating after a while… you can feel like you're fighting a losing battle."* (David)

> *"It (dissenting) was really difficult and it used to just make me feel…like, oh you silly girl, you stepped out of line, why don't you just keep your head down…"* (Kirsty)

Compromise: strategically "stepping into" the medical model

Some participants adopted a pragmatic approach. When they felt it was in their clients' best interests, they would sometimes temporarily "step into" the model, either joining in with discussions couched in medical terms, or just keeping quiet.

> *"It's about picking battles… I don't want… it to be a bit of a power battle… that could very well backfire.* (Patrick)

> *"I'm aware of the inconsistency in my positions, but I'm also pragmatic…weighing up the benefits of getting more psychological therapy against the cost of not…challenging the notion of schizophrenia actually existing."* (Helen [on securing extra resources by citing national guidelines predicated on the idea of "schizophrenia"])

On a practical level, participants found that it was important to pick one's battles. As Patrick put it, constantly arguing with other team members "would make professional life just too difficult". This is consistent with Johnstone's (2011) view that "It is impossible to work as a critical psychologist on, for example, an in-patient ward and not collude to some extent; if you object to every use of psychiatric labelling, your role will be impossible" (p. 102) . It is also consistent with Court, Cooke & Scrivener's (2016) finding that clinical psychologists drew strategically on the "discourse of power" associated with diagnosis-driven clinical guidelines in order to achieve ends they believed in.

Colluding: inadvertently slipping into the medical model

Compromise could easily become collusion: a number of participants described the sobering experience of finding that they had unintentionally "slipped into" a medicalised way of talking or even thinking.

> *"I think that it's quite easy even against your better judgement to get drawn into…using the language and ideas just because it's there"* (Patrick)

This left them feeling guilty and questioning their ability to remain true to their values.

> *"I think it's quite easy to get caught up in quite a lot of guilt about it…"* (Patrick)

Strategies for working helpfully and sustainably in medicalised systems

Finally, the participants described the strategies that enabled them to continue working in the system in a way that they hoped was helpful, and which was also practically and emotionally sustainable. These are outlined next and included *client-related, team-related, self-related, support-related* and *political* strategies.

Client-related strategies included:

Focusing on clients. Participants described how they drew encouragement from their clients' progress. Some identified more with their clients than with their teams and saw championing their interests as a key priority.

> *"I don't feel listened to, so I know what it feels like to be not listened to… I identify with the clients in that way"* (Jennifer)

> *"I see myself working with the system but as an advocate for the client"* (Jennifer)

This strategy may have its limitations. Stokes (1994) suggests that idealising the "pairing" between themselves and the client can lead therapists to overestimate the helpfulness of their interventions. The first author remembers being told by a service user academic "the trouble with clinical psychologists is you think you're the good guys" (D. Rose, personal communication, 2003). Pilgrim (2005) reminds us that the system is not only about care but also social control, and all staff who work in it are part of that.

Foregrounding clients' contexts and understandings. A number of participants highlighted the importance of basing interventions on clients' own understanding of their problems:

> *"In therapy I take as my starting point the client's interpretation and meaning…"* (Helen)

This is consistent with recent guidance from the BPS Division of Clinical Psychology:

> *"Professionals need to work with people's own ideas about what might have contributed to their problems… professionals should not promote any one view, or insist that any one form of help such as medication or psychological therapy is useful for everyone"*. (Cooke, 2017a, p.103).

Holding the tension between "expert" and "not-knowing" approaches. Some participants felt it important to adopt a curious, "not-knowing" (Anderson, 2005) approach. However, there were also times when they felt it necessary to assert their professional expertise and authority within their teams. Finding a way of managing the tension between these two stances had been key.

> *"I work very hard at trying not to be an expert. At times… I need, or people are actually requiring me, to be one…. Getting to grips with this and feeling okay about it has been important."* (Kirsty)

Using ordinary language: Many participants described using clients' own words rather than professional jargon.

> *"I…just try… my best to describe… what this person is experiencing using the words they use"* (Kristy)

This is consistent with Hulme's (1999) suggestion that psychotherapy can often be more usefully conceptualised – and practised – as "collaborative conversation". It is also evocative of what service users named as one of the most important attributes for a professional: "staying human" (Lea, Holttum, Cooke, & Riley, 2016). Using everyday language can also be seen as an act of resistance in an environment dominated by a hegemonic medical discourse (Harper, 1995).

Team-related strategies included:

Forging robust working relationships. Participants described the importance of finding allies within their teams and fostering good working relationships. This enabled them to be critical of ideas and practices without fellow team members taking it personally.

> *"It's about having robust enough relationships with people where you are able to say, look this is my view about this particular thing and it's not actually about my relationship with you…"* (Kristy)

Being mindful of difference and of constraints on colleagues. Many participants tried actively to bear in mind the constraints to which other team members were subjected, the pressures on them, and the nature of their training.

> *"It's helpful to hold onto the thought that they're doing that not because they're trying to be evil or controlling or punitive: they're doing it because they believe it's the right thing to do and how they've been trained."* (Kristy)

Recognising one's power and ability to influence. Participants felt able to use their power for good within the system, for example shaping services or offering training and supervision to colleagues. Parker (1993) found that perceived self-efficacy and power over decision-making was positively related to willingness to engage in "reformist dissent" within the health service.

> *"I've gathered the support of almost the entire organisation …we* (clinical psychologists) *don't just follow protocols, we develop protocols…"* (Jennifer)

Self-related strategies included:

Self-care and work/life balance: Many participants said that self-care, outside interests and boundaries between work and home had enabled them to remain productive and engaged. This is perhaps unsurprising and consistent with other accounts of strategies that professionals use to avoid burnout (e.g.Schaufeli, Maslach, & Marek, 2017).

> *"I try not to work overtime and to use my journey home to kind of shake all this out of my head…"* (Anthony)

Taking encouragement from small changes. A number of participants took encouragement and motivation from noticing even small positive changes to which they had contributed.

> *"I try, as I leave work at the end of the day, to identify one small thing that I feel has made a difference to someone's life or the system."* (Jennifer)

Consolidating a personal philosophy. Some participants stressed the importance of articulating a coherent personal philosophy. This gave them confidence that their alternative views were "good enough" and enabled them to speak out when necessary.

> *"It's about how you can be comfortable with your own efforts and find your own way, your place in the system."* (Helen)

Support-related strategies included:

Mutual support and solidarity. Many participants highlighted the importance of being part of a network of professionals with similar views. This finding is in keeping with more general literature on coping, which stresses the importance of solidarity and social networks (Viswesvaran, Sanchez, & Fisher, 1999). Having regular supervision with another clinical psychologist was also described as very useful.

> *"It's a great source of strength, getting support from within the profession and being part of local and national networks, people who share your views…"* (David)

Drawing on scholarship. Many participants drew on academic and service user scholarship. Some described it as helping to "crystallise" their thinking, to remind them that they were not alone in their views, and to justify their position:

> *"I have a bookshelf stacked full of books… just having them there helps me because I know there are ideas in those books that are supportive of what I'm doing"* (Natasha)

> *"I gave the psychiatrist some papers supporting my view and that felt good, to know I was talking with some authority"* (David)

Political strategies

Engaging in activism outside work. Finally, many participants found that engaging in political activity and campaigning outside work had helped them to reconcile their ambivalence about working within the system.

> *"I'm quite heavily politically involved…so all the small spats I have locally, I get through that by…getting stuck into bigger spats nationally…"* (Anthony)

This is consistent with Gelsthorpe's (1997) and Cooke's (2017b) suggestion that clinical psychologists should engage politically to change the system:

> *"We need to get over our ivory tower preciousness, our worry about what our colleagues will think, and get involved in the public debate… For many of us this is why we belong to the BPS* [British Psychological Society] *– to join together and make a difference in the world"* (Cooke, 2017b, p. 63)

One way of conceptualising such political engagement is that of social justice advocacy.

Mallinckrodt, Miles & Levy (2014) propose a "scientist-practitioner-advocate model" of clinical psychology training which "incorporates social justice advocacy, thereby equipping graduates to address social contexts implicated in clients" suffering instead of only the symptoms' (p.303).

Implications

The current study has illustrated how in a medicalised system, offering an alternative perspective can be difficult, despite many psychologists seeing this as one of their key roles (British Psychological Society (BPS), 2007). It has implications not only for clinical psychologists but also for other psychosocially oriented workers.

Participants' accounts suggest that for some teams, medicalisation may be an anchor which enables them to manage the anxiety arising from the complexity and uncertainty of their work, from the distress to which they are exposed daily, and from social expectations that they will eliminate risk (Nalletamby, Marsh and Cooke, forthcoming). This process may help to maintain the hegemony of the medical model despite the problems of the latter. It may also lead to a perverse situation where some workers feel unable to do what they came into the field to do, namely to have helping conversations:

'Staff become passive sentinels guarding and overseeing the delivery of medication cocktails… they become diffident to a source of knowledge beyond their daily grasp. This helplessness extends across their work, limiting their sense of competence when…practical support and enquiry through gentle, respectful curiosity are essential. (Diamond, 2013, p. 321.)

Ironically, in the longer term adherence to a medicalised discourse may help to maintain the "blame" culture by promulgating the narrative of the "expert helper" who can avoid adverse outcomes by conscientious application of procedure (cf. "Zero Suicide"; McGowan, 2018). Before change can happen, open discussions will be needed about these issues both at a policy level and within individual teams. Clinical psychologists are well placed to instigate and participate in these. The recent publication of the Power Threat Meaning Framework (Johnstone et al., 2018) as an alternative to the diagnostic frame may be a useful prompt for such discussions, and the document a useful resource.

Limitations

Due to the sampling strategy the findings may not represent the experiences of all clinical psychologists working in the mental health system. Indeed, a criterion for inclusion was that participants described themselves as critical of the medical model. The issues may also be slightly different for other professionals.

However, generalisability is not the aim of grounded theory: the aim was to explore the experiences and insights of these particular psychologists in order to contribute to theory development. It would be useful to conduct a larger study to elucidate how typical these findings are of clinical psychologists in general or of other psychosocially oriented professionals.

It is nevertheless clear that it is at least possible for practitioners critical of the medical model to find ways of surviving and making a difference within our current, medically dominated mental health system. Despite its limitations we hope that this is a useful account and analysis both of the difficulties and of strategies that can help. We hope that not only psychologists but other workers will find it useful when grappling with their own dilemmas.

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"But What About Real Mental Illnesses?" Alternatives to the Disease Model Approach to "Schizophrenia"

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Abstract

The old dichotomy between "neurosis" and "psychosis" appears to be alive and well in the debate about psychiatric diagnosis. It is often suggested that while diagnostic alternatives may be appropriate for the relatively common forms of distress with which we can all identify such as anxiety and depression, psychiatric diagnoses remain vital for experiences such as hearing voices, holding beliefs that others find strange, or appearing out of touch with reality—experiences that are traditionally thought of as symptoms of psychosis. Such experiences are often assumed to be symptoms of underlying brain pathology or "real mental illnesses" that need to be diagnosed or "excluded" (in the medical sense of ruling out particular explanations of problems) before deciding on the appropriate intervention. This article argues that this belief is misguided, and that far from being essential, psychiatric diagnosis has the potential to be particularly damaging when applied to such experiences. It describes an alternative perspective outlined in a recent consensus report by the British Psychological Society Division of Clinical Psychology (*Understanding Psychosis and Schizophrenia*), which has attracted significant attention in the United Kingdom and internationally. The report argues that even the most severe distress and

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the most puzzling behavior can often be understood psychologically, and that psychological approaches to helping can be very effective. It exhorts professionals not to insist that people accept any one particular framework of understanding, for example, that their experiences are symptoms of an illness. This article outlines that report's main findings, together with their implications for how professionals can best help.

Keywords
psychosis, schizophrenia, mental illness, psychosocial models, alternatives to diagnosis, British Psychological Society

The theme of this special edition is the limits of, and alternatives to the practice of diagnosis in the field of mental health. Some have argued that psychiatric diagnosis is merely a method of classification with no conceptual baggage: Indeed, the *Diagnostic and Statistical Manual of Mental Disorders*, Fourth Edition (*DSM-IV*) was explicit that it was "*neutral with respect to theories of etiology*" (American Psychiatric Association, 1994, p. xviii). However, as other contributors have made clear, the origins, assumptions, and implications of "diagnosis" are closely linked to one particular approach to problematic feelings, experiences and behaviors, namely the "medical" or "disease" approach. Interestingly, *DSM-5* makes no claim of theoretical neutrality (Tsou, 2015). While highly contested (e.g., Johnstone, 2014; Kinderman, 2014; Read & Dillon, 2013) the disease model is so widespread in our society as to be unquestioned or "taken for granted" (Andrews, 2012) by many. It views puzzling experiences and problematic emotional states as symptoms of "mental illnesses," which can be diagnosed and treated in the same way as say, malaria or diabetes.

Many of us are keenly aware of the limitations of this approach with regard to experiences with which we can all identify such as low mood and excessive fearfulness, traditionally thought of as the "neuroses" of depression and anxiety respectively. Despite appearing in diagnostic textbooks, these experiences are widely acknowledged to be often, at least in part, understandable reactions to life circumstances. However, the same does not necessarily apply to those experiences such as hearing voices, holding beliefs that others find strange, or appearing out of touch with reality, which are traditionally thought of as symptoms of psychosis. Many people, both lay and professional, believe that there remain some experiences which are symptoms of illness, perhaps arising primarily from something going wrong in the brain (e.g., Frances, 2014). The archetypal such "mental illness" is schizophrenia, and many otherwise critical commentators (e.g., Frances, 2014; Frith, 2015) are keen to distinguish it from more "normal," understandable psychological problems. The grounds for this distinction appear to be both theoretical (a belief that certain experiences are markers of underlying biological illness) and practical (a wish to ensure, e.g., that the people concerned receive appropriate care and do not end up in unhelpful environments such as prison (e.g., Frances, 2014).

Despite its current dominance, this view has been subject to increasing challenges, particularly in the United Kingdom, where a body of work built up over the past 20 years (e.g., Bentall, 2003; Freeman et al., 2012; Morrison, 2001) suggests that even the most severe distress and the most puzzling behavior can often be understood psychologically in the same way as "normal" anxiety or sadness. Moreover, there is evidence that psychological approaches to helping can be very effective, and that psychiatric medication is not always needed (e.g., Garety & Freeman, 2013; Morrison, Hutton, Shiers, & Turkington, 2012, Morrison et al., 2014).

This body of work acknowledges that there are many different theories as to what causes experiences such as hearing voices, and that the unique combination of interacting "causes" is likely to be different for each person. The idea that these experiences are symptoms of illness, perhaps caused by some sort of chemical imbalance or other problem in the brain, is just one of the theories. Even though schizophrenia is arguably regarded as the archetypal "mental illness," there is no objective biological test for it such as a blood test or scan, and it remains essentially an *idea*. Indeed, when biological research indicates risk factors for (and therefore possible blood tests for biomarkers of) such experiences, these biological risk factors tend to relate to patterns of psychological experience that cut across diagnostic boundaries (Cross-Disorder Group of the Psychiatric Genomics Consortium, 2013). Moreover, there is a vigorous debate about whether the very idea of "mental illness" is meaningful or useful.

The issues most often debated include (a) the extent to which psychotic experiences can be separated from "normal" ones; (b) the frequency with which "normal" as well as "ill" people have certain experiences, for example, hearing voices; (c) the extent to which clinicians can agree on a diagnosis (reliability); (d) whether mental illnesses such as schizophrenia are real "things" (validity); and (e) the advantages and disadvantages of seeing things as illness (utility) (see, e.g., Kinderman, Read, Moncrieff, & Bentall, 2013).

The British Psychological Society Report "Understanding Psychosis and Schizophrenia"

The British Psychological Society (BPS) has taken a critical position with regard to psychiatric diagnosis, both in general and with regard to schizophrenia in particular. Its 2011 response to the American Psychiatric Association's (APA's) proposals for *DSM-5* stated that

> clients and the general public are negatively affected by the continued and continuous medicalization of their natural and normal responses to their experiences; responses which undoubtedly have distressing consequences . . . but which do not reflect illnesses so much as normal individual variation . . . This misses the relational context of problems and the undeniable social causation of many such problems (BPS, 2011, p. 2).

The BPS Division of Clinical Psychology (DCP), which represents the majority of psychologists working in mental health settings, has explicitly criticized current systems of psychiatric diagnosis, suggesting that "there is a need for a paradigm shift in relation to the experiences that these diagnoses refer to, towards a conceptual system which is no longer based on a 'disease' model" (BPS DCP, 2013, p. 1). Recent DCP guidelines on language use suggest that psychologists should "avoid the use of diagnostic language in relation to the functional psychiatric presentations" (BPS DCP, 2015, p. 2). Its suggested alternative is to adopt an individualized approach, "collaborative formulation" (BPS DCP, 2011). Formulations explore the personal meaning of the events, relationships and social circumstances of someone's life, and of their current experiences or distress. The person experiencing the difficulty works together with the professional to develop a hypothesis, or best guess, which can provide a basis for finding a way forward. Unlike a diagnosis, formulation is based on the assumption that however extreme, unusual or overwhelming the nature of that distress ". . . at some level it all makes sense" (Butler, 1998, p. 2; see also Johnstone, 2017). Formulations are an answer to the "brain or blame" dilemma mentioned below: They make sense of problems in a way that neither implies that people are to blame, nor that their problems are 'all in the mind.'

A significant development was the publication in 2014 by the BPS DCP of its report *Understanding psychosis and schizophrenia: why people sometimes hear voices, believe things others find strange, or appear out of touch with reality, and what can help* (Cooke, 2014). The report, freely available to download, summarized the current state of knowledge and debate in the field, together with relevant academic references, and outlined a psychological approach. It was written for service users (consumers), journalists and the general public as well as professionals, and attracted significant attention in the UK and world media. The current first author (AC) was the editor of the report and the second author (PK) was a major contributor (Cooke & Kinderman, 2014, 2015). A revised version (Cooke, 2017) was published in 2017. The report is freely available to download from www.understandingpsychosis.net. The next section will summarize the motivation behind it, and its major messages.

Summary of Content

The report argues (inter alia) that hearing voices and feeling paranoid are common experiences, which can often be a reaction to trauma, abuse, or deprivation. Calling them symptoms of mental illness, psychosis, or schizophrenia is only one way of thinking about them, with advantages and disadvantages. The report summarizes evidence that there is no clear dividing line between "psychosis" and other thoughts, feelings, and beliefs (e.g., Verdoux & Van Os, 2002): Psychosis can be understood in the same way as other psychological problems such as anxiety or shyness (e.g., Freeman, 2007; Freeman et al., 2012; Morrison, 2001). While acknowledging that for some people experiences of psychosis can be lifelong and disabling, and that offering help to those affected needs to be a major national priority, the report also reminds us that for many people such experiences are short-lived. Even people who continue to have them nevertheless often lead happy and successful lives (Slade, Amering, & Oades, 2008).

Turning more specifically to the issue of diagnosis, *Understanding Psychosis and Schizophrenia* acknowledges that some people find it useful to think of themselves as having an illness. But others prefer to think of their problems as, for example, an aspect of their personality which sometimes gets them into trouble but which they would not want to be without (see, e.g., The Icarus Project, 2013). In what is perhaps its key message, the report exhorts professionals not to insist that people accept any one particular framework of understanding, for example, that their experiences are symptoms of an illness. Even the title of the report was a matter of some debate, for example whether the word 'schizophrenia' should be in intervened commas or even used at all. In the end we decided that it was necessary in order for the report to come up in internet searches, but that it was important also to have a subtitle demystifying the term.

After diagnosis, the report moves on to implications for intervention, summarizing research suggesting that psychological therapies can be very helpful for many people who experience psychosis (see, e.g., Morrison et al., 2014), including those who choose not to take medication. However, only a small minority of those affected are able to access psychologically informed services, with the vast majority still being told that they have a mental illness and offered only medication (Schizophrenia Commission, 2012). While many people find that neuroleptic drugs help to make the experiences less frequent, intense, or distressing, there is no evidence that they correct an underlying biological abnormality. More generally, it is vital that services offer people the chance to talk in detail about their experiences and to make sense of them. Despite this being what most people think mental health *services* offer, surprisingly few currently do.

Turning to the issue of causation—etiology, in medical language—*Understanding psychosis and schizophrenia* presents evidence that psychosis is often related to experiences of abuse, deprivation, victimization, and racism (e.g., Fearon et al., 2006; Varese et al., 2012). There is also racism in services: People from black and minority ethnic communities are more likely than others to be diagnosed with schizophrenia (e.g., Delphin-Rittmon et al., 2015; see also Metzl, 2009), more likely to experience compulsion (Care Quality Commission, 2011) and less likely to be offered psychological therapy (Mind, 2013). (The revised version, published in 2017, addresses these issues more fully). The report argues that services need to change radically, and that as a society we need to invest in prevention by taking measures to reduce abuse, deprivation, and inequality.

Problems With the Idea of "Schizophrenia"

Drawing on the BPS report, but also on other sources, we now address the question: How meaningful or useful is it to conceptualize the experiences described above as symptoms of diagnosable "mental illnesses" such as schizophrenia? Similar arguments apply to other "mental illness" diagnoses such as bipolar disorder (see, e.g., Jones, Lobban, & Cooke, 2010).

The Continuum: "Psychotic" Experiences Cannot Be Separated From Normal Ones

It is often assumed that there is a discrete, identified disease process (most commonly "schizophrenia") underlying experiences such as paranoia or hearing voices. However, evidence suggests that there is no straightforward dividing line between "mental health" and "mental illness" (normality and abnormality). Instead, there appears to be a continuum between good and poor mental health along which we all move up and down throughout our lives (Cromby, Harper, & Reavey, 2013; Verdoux & Van Os, 2002). At different times we may be more or less anxious, depressed, or suspicious, for example. Such feelings and beliefs often develop in response to stressful life events and are moderated both by the degree of support available to us and by the opportunities we have to make sense of what is happening (Andrew, Gray, & Snowden, 2008). The tendency to hear voices or to experience suspiciousness or paranoia also varies between individuals as part of a spectrum of complex personal traits and characteristics in the population (Bentall, 2003). On a number of dimensions, people range from being conventionally "normal" to quite unusual. For example, most of us hold beliefs that some others find odd, but sometimes these beliefs are relatively common (e.g., in Western society, the belief that Jesus was divine or that mediums can communicate with the dead) and sometimes quite unusual (e.g., that a particular mark on our skin was put there by aliens and is highly significant).

This "continuum" view is widely accepted with respect to experiences such as anxiety. Individuals differ in terms of how anxious they are in general. This may be an enduring characteristic of their personality, and is likely to involve a combination of genetic factors and upbringing. Only a minority will ever experience extremes of anxiety such as a series of panic attacks, which are recognized in the diagnostic textbooks as justifying a diagnosis of panic disorder. Similarly, there is evidence that the state of extreme suspiciousness commonly known as paranoia is an extension of the feelings of suspiciousness that we all feel from time to time (Freeman et al., 2005). People differ in this regard: Everyone knows people with whom we have to be very careful what we do or say lest they interpret it as an insult. Similarly, situations vary in their tendency to provoke suspiciousness. We have all been in situations where it makes sense to be extra vigilant, for example walking home alone late at night; in such situations, it is easy to be frightened by even the most innocent things. A quote from a member of the public (quoted in the BPS, 2014, report) illustrates this point:

> I felt quite lonely and isolated at school. Even though I had a few friends, I still felt left out and I remember that I started to think that when kids were laughing, that they may have been laughing at me. At the time I knew this was probably wrong, but I couldn't help it, and it started to make me feel even more uncomfortable around school . . . After university . . . probably as a result of being isolated again, the thoughts began to come back. However, this time I began to be under the impression that I had some sort of social handicap, similar to autism, and that people could tell this just by the way that I did or didn't make eye contact with them. Consequently, going out on the street became an ordeal because the more self-conscious I felt about my eye contact, the more uncomfortable I felt when looking at people. Eventually, I was convinced that when I was out on the street, everyone who saw me instantly knew I had some sort of social handicap. It actually started to feel as if everybody who met me pretended to treat me normally and then laughed at me behind my back once I'd gone. (Adam, quoted in Cooke, 2017, p. 18)

Many "Normal" People Have "Psychotic" Experiences

A second finding that casts doubt on the assumption that experiences such as hearing voices are necessarily part of an illness is that such experiences appear to be quite common. Many healthy, well-functioning people sometimes have "abnormal" experiences. For instance, many people have heard voices at some point in their life (Beavan, Read, & Cartwright, 2011), and nearly one in three people may hold a belief that clinicians might consider paranoid (Bebbington et al., 2013). The latter authors concluded that "paranoia is so common as to be almost normal" (p. 425).

Only 1 in 50 people who have "psychotic-like" experiences appear to meet *DSM* criteria for schizophrenia (Hemsley, 1993). Extreme circumstances such as sensory or sleep deprivation can lead to various disturbances, including paranoia and hallucinations in people who never previously had such experiences (Jackson, Hayward, & Cooke, 2011). Some people who experience visual or auditory hallucinations consider them spiritually enriching (Clarke, 2010; Heriot-Maitland, Knight, & Peters, 2012; Romme & Escher, 1993). There is huge diversity in the way that experiences are understood in different cultures. For example, cultures and subcultures vary with regard to whether particular experiences are seen as signs of mental illness, as normal (religious and spiritual beliefs, for example), or even as revered gifts (Bhugra, 1996). These findings suggest that although psychotic experiences can be distressing and disabling for some, others experience them as helpful and life enhancing. Of course, for many people they can be both, either at different times or even at the same time: a "dangerous gift" (The Icarus Project, 2013).

It appears, then, that "psychotic" experiences are more common than is frequently assumed and also shade imperceptibly into 'normal' ones. Turning to the remaining three points referred to above, there are also significant problems with the reliably, validity, and utility of the schizophrenia diagnosis.

The Schizophrenia Diagnosis Is Unreliable

DSM-5 (APA, 2013, pp. 99-100) criteria for schizophrenia are as follows:

> All criteria (A–E) must be met:
>
> A. Characteristics: Two or more of the following, each present for a significant portion of time during a 1-month period (or less if successfully treated). At least one of these must be (1), (2), or (3):
>
> 1. Delusions
> 2. Hallucinations
> 3. Disorganized speech
> 4. Grossly disorganized or catatonic behavior
> 5. Negative symptoms (i.e., diminished emotional expression or avolition)

B. Social/occupational dysfunction: For a significant portion of the time since the onset of the disturbance, level of functioning in one or more major areas, such as work, interpersonal relations, or self-care, is markedly below the level achieved prior to the onset (or when the onset is in childhood or adolescence, there is failure to achieve expected level of interpersonal, academic, or occupational functioning).

C. Duration: Continuous signs of the disturbance persist for at least 6 months. This 6-month period must include at least 1 month of symptoms (or less if successfully treated) that meets Criterion A (i.e., active-phase symptoms) and may include periods of prodromal or residual symptoms. During these prodromal or residual periods, the signs of the disturbance may be manifested by only negative symptoms or by two or more symptoms listed in Criterion A present in an attenuated form (e.g., odd beliefs, unusual perceptual experiences).

D. Ruling out of other disorders: Schizoaffective disorder and depressive or bipolar disorder with psychotic features have been ruled out because either (1) no depressive or manic episodes have occurred concurrently with the active-phase symptoms, or (2) if mood episodes have occurred during active-phase symptoms, they have been present for a minority of the total duration of the active and residual periods of the illness.

E. Attributes: The disturbance is not attributable to the physiological effects of a substance (e.g., a drug of abuse, a medication) or another medical condition.

F. History: If there is a history of autism spectrum disorder or a communication disorder of childhood onset, the additional diagnosis of schizophrenia is made only if prominent delusions or hallucinations, in addition to the other required symptoms of schizophrenia, are also present for at least a month (or less if successfully treated).

Reliability has been improved by the "tick-box" approach taken by recent editions of *DSM* (APA, 1980, 1994, 2013) as exemplified by the criteria for schizophrenia outlined above. However, it remains low (Carney, 2013), particularly in everyday clinical practice where diagnoses are often made without detailed reference to *DSM* criteria (Kirk & Kutchins, 1994). Clinicians tend to have diagnostic "preferences" and people are often given a range of diagnoses during their contact with mental health services, as illustrated by these quotes taken from the BPS report:

> I was labelled with all sorts: eating disorder not otherwise specified, major depressive disorder, borderline personality disorder, schizoaffective disorder

> and eventually schizophrenia . . . that was the one that knocked the stuffing out of me completely. What was the point in fighting if I was going to be suffering from a lifelong brain disease forever? (Sally Edwards quoted in Cooke, 2017, p. 12)

> My psychiatrist gave me various mental health labels . . . She told me I had what was called "schizophrenia" by the professionals. However, my mother, who had recently trained as a counsellor and well understood the ramifications of this, was concerned at the possibility of this becoming my diagnosis and the effect this might have on my long term life prospects. She asked the professionals to reconsider, and I was then told I had bipolar, which I later learnt is sometimes seen as being a slightly less (though not always much less) socially damaging diagnosis. I wonder if the professionals would have reconsidered in the way they did, had my mother had less wherewithal to challenge the establishment or had not spoken fluent English? I doubt it. (Raza Griffiths quoted in Cooke, 2017, p. 22)

Diagnostic usage varies between different clinicians, hospitals, and countries. Even experienced clinicians who have been given extra training in applying the criteria only agree on a broad diagnostic category about 50% of the time (Carney, 2013; Kirk & Kutchins, 1994). The reliability of the schizophrenia diagnosis in the field trials prior to the publication of *DSM-5* was particularly worrying (Cooper, 2014).

The Schizophrenia Diagnosis Is Invalid

> The tendency has always been strong to believe that whatever has a name must be an entity or being, having an independent existence of its own. And if no entity answering to the name could be found, men did not for that reason suppose that none existed, but imagined that it was something peculiarly abstruse and mysterious. (John Stuart Mill, 1869/2014)

One argument that is often put forward by those who favor the idea of schizophrenia is that the experiences and behaviors that can lead to the diagnosis are very real. As someone said to us recently, "Just spend a couple of hours on my ward and you'll see beyond any doubt that schizophrenia exists."

It is of course true that experiences such as hearing voices are very real for the person concerned, and that they can lead both to distress that is very real and to behavior that is hard to understand. However, this does not mean that they are necessarily symptoms of real "illnesses." Giving something a name, and even being very clear about its definition, does not necessarily imply that it necessarily exists in reality. Most people would agree on how to identify a unicorn, for example, even though they are mythical rather than real creatures. The problem is that the existence of the label can give the misleading impression of the existence of the "thing." Van Os (2009) explains it in these terms: "The complicated, albeit ultimately meaningless, Greek term suggests that schizophrenia really is a 'thing,' i.e. a 'brain disease' that exists as such in nature. This is a false suggestion" (p. 368).

So the question at issue is the extent to which the label of "schizophrenia" refers to a meaningful entity in the real world, in other words its validity. Just as with low mood or anxiety, whilst the experiences and distress are very real, the explanation—that there is an illness called "schizophrenia" causing them—is increasingly contested.

The usual meaning of the term *diagnosis* includes ideas of causation and prognosis as well as categorization: in most of medicine, a diagnosis not only categorizes but also explains, indicating the cause of the problem, what is likely to happen over time and what can be done about it (see Johnstone, 2014 for a fuller discussion). However, as Lucy Johnstone (2017) explains, this is not the case for mental health "diagnoses," which rather than being explanations, are simply ways of categorizing experiences based on what people tell clinicians. It makes no more sense to say that someone hears voices because they "have schizophrenia" than it would do to say someone has a cough because they "have cough disorder" (Robinson, quoted in Shariatmadari, 2015). Although some scholarly writing (including *DSM-IV*; APA, 1994, as noted above) acknowledges this, much does not and it is rarely acknowledged in public information materials (see, e.g., APA, n.d.).

Turning to "prognosis," outcome is very variable (Kinderman et al., 2013) and there is also very little evidence that diagnoses are useful in guiding treatment (Moncrieff, 2013).

The Idea of Schizophrenia May Be Doing More Harm Than Good

Our argument thus far can be summarized as: schizophrenia is essentially an *idea*. The view that experiences such as hearing voices are symptoms of an underlying illness is only one way of understanding them, and one that is highly contested. There are problems with both the reliability and validity of the diagnosis.

So the question arises: If the idea of schizophrenia is only one possible way of conceptualizing the phenomena in question, is it—and by extension the whole idea of "mental illness"—a helpful or useful idea?

The idea of mental illness certainly has some advantages: it gives us a way of talking about difficult things and a framework for offering help, as well as time off work with sick pay or benefits if needed and access to services. It provides a shorthand for people involved in planning services or efforts at prevention. Some of those personally affected welcome a diagnosis because it implies that they are not alone in what they are experiencing (e.g., Falk, 2010, quoted in Jones et al., 2010, p. 32). Others are concerned that unless they are seen as "ill," people will blame them or their family for their predicament. This has been called the "blame or brain" dilemma (Boyle, 2013). In summary, the idea of mental illness fulfills—within our current culture and social structures—three vital functions, namely access to validation, income, and support. Those critiquing diagnosis and suggesting alternatives need to bear this in mind and ensure that our critiques do not—particularly in the current Zeitgeist of "austerity" and cuts to services—lead to unintended consequences, for example, being used as an excuse to reduce vital support.

In other ways, thinking in terms of illness can be unhelpful and many have argued that overall, the idea of mental illness may do more harm than good (e.g., Cooke, 2008; Hickey, 2015; Johnstone, 2014; Kinderman, 2014). People can feel labeled as "mental patients," disempowered, and sometimes even excluded from mainstream society (Horn, Johnstone, & Brooke, 2007). A recent review of the experience of "stigma" (Young Minds, 2010) found that for many people, being seen as mentally ill causes more distress than their original problems. Evidence suggests that people seen as mentally ill are often avoided, treated harshly, and subject to discrimination (Cooke, 2008; Cooke & Harper, 2013; Read, Haslam, Sayce, & Davies, 2006; Social Exclusion Unit, 2004). For example, although having a job can be very important in people's recovery, employers are less likely to offer work to someone if they know that they have a psychiatric diagnosis (Mehta & Farina, 1997). Reviews of the available evidence suggest that viewing distress as "an illness like any other" can actually increase prejudice and discrimination (Angermeyer, Holzinger, Carta, & Schomerus, 2011; Read et al., 2006). For example, in one study, participants who were told that another person (actually a researcher) had a mental illness opted to give them more electric shocks than if the person's problems were described in more everyday language (Mehta & Farina, 1997). The shocks were fake, but the participants were only told that afterward. These authors suggest that presenting problems as an "illness" has the effect of making them seem mysterious and unpredictable, and the people experiencing the problems as "almost another species."

Schizophrenia is arguably the archetypal "mental illness" (Cooke, 2008) and its implications may be even more damaging than is the case with other diagnoses. The usual stereotype can perhaps be summed up as: Someone who has psychotic experiences is different from normal people, because his brain (note that the stereotype includes the presumed gender of the individual) is damaged or different, probably because of his genes. He is "a schizophrenic," who is not understandable, is dangerous, has no legitimate voice and requires control through drugs that target the underlying brain disorder. This stereotype is reflected in, and appears to be maintained by media coverage (e.g., Parry & Moyes, 2013). It is important to remember that those affected by this stereotype include those who are themselves diagnosed with schizophrenia. Some readers may have seen the documentary *Stranger on the Bridge* (Forsdyke, 2015) made by Jonny Benjamin, who considered suicide after being diagnosed with schizophrenia. Interviewed by a journalist, he explained "All I knew was what I read in the papers, that people with schizophrenia are violent and incapable of recovery" (O'Hara, 2013).

While some have argued that efforts need to be directed at "rehabilitating" the concept of schizophrenia in the public mind, perhaps by "reclaiming" it (as has happened with other originally stigmatizing terms such as "queer"), others have argued that the social meaning of the concept is so ingrained that such attempts are doomed to failure (Cooke & Harper, 2013; Corrigan & Watson, 2004; Hammersley & McLaughlin, n.d.).

Receiving a diagnosis can also have other negative psychological effects on the person, for example, leading to feelings of hopelessness and decreased confidence. It can give the message that people can do little to overcome their problems except to "keep taking the tablets." It can divert attention from the personal meaning of the experiences for the person, together with any positive aspects (Herman, 1997).

These disadvantages are illustrated by the following quotes by people who have been given diagnoses of schizophrenia or other "psychoses":

> I was told I had a disease . . . I was beginning to undergo that radically dehumanizing and devaluing transformation . . . from being Pat Deegan to being "a schizophrenic." (Deegan, 1993, p. 7)

> Being given a diagnosis is like a kick in the teeth. They're not saying that there's something wrong with your liver, but that something is wrong with you. (Anon, in Jones et al., 2010, p. 65)

> For a number of years, I accepted the medical model as a framework of understanding . . . But I gradually came to appreciate drawbacks to the framework. My reading suggested the model might not stand up scientifically. The emphasis on distress as illness not only encouraged a resort to exclusively physical treatments (drugs, ECT) but pushed to one side any consideration of the content and meaning of my crisis episodes. Thinking of myself as having a

> chronic and incurable illness robbed me of power and agency and confined me within an essentially negative category. By the time I was entering my second decade of service use, the medical model, which I had initially found reassuring, seemed increasingly unsatisfactory, without the capacity to encompass the complexity of my interior or exterior life and give it positive value. As a result, I began to actively explore frameworks that better met my needs. (Campbell, 2010, p. 22)

> Once past the "relief response" on learning a name for the distress—the label itself does not alleviate the pain. It does not help the professional or the individual to understand what is happening or what would assist the individual. It stops the individual from owning the experience and finding his/her own language and interpretation. . . . the labelled people are seen as inferior or less competent . . . People become dependent and helpless with the treatments and labels. (Pembroke, 2012, p. 32)

It therefore appears clear that the idea of schizophrenia can have negative effects on those diagnosed. It has also arguably led to professional myopia regarding the events and circumstances of people's lives that may, for many, be the major reason that their difficulties have developed (Midlands Psychology Group, 2012), diverting attention from underlying social and emotional problems that could otherwise be addressed in a restorative way, for example the aftermath of adversities like poverty, discrimination, childhood abuse, or assault (Campbell, 2010). The way that diagnoses appear to summarize the nature and causes of someone's experience can prevent workers from asking about, and helping the person to deal with the events and emotions that may in reality underlie their problems. The idea of schizophrenia can lead to misplaced certainty, where assumptions about cause and effect are unquestioned and a particular view and particular interventions are imposed on the service user, by force if necessary. It can also divert our focus from efforts at prevention which could arguably make a far bigger difference overall to rates of psychosis (Boyle, 2004). As our colleague John Read has put it "Why do we neglect prevention? The best way of reducing rates of psychosis would be to reduce childhood adversity" (Read, 2014). As the saying goes in public health circles, perhaps mental health services are often "trying to mop the floor while the water is still running."

So Why Is the Idea of Schizophrenia Still so Engrained and Popular?

As outlined above, there is increasing acceptance both that "psychotic" experiences are a relatively normal and common phenomenon and that there are significant problems with the reliability, validity, and utility of the diagnosis of schizophrenia. Nevertheless, the idea of schizophrenia remains a very popular one both in the scientific literature and in the popular imagination. Most lay people are unaware that there might be any other explanation for the phenomena in question. We have been struck by the surprise with which journalists and others react to the news that there is no blood test for schizophrenia, for example. So why might this be? What factors might be contributing to the ongoing popularity of schizophrenia as an idea?

Part of the explanation might be the "clinician's illusion." This is a form of "Berkson's bias" (Berkson, 1950; Maric et al., 2004), namely the tendency to conclude that two things are related when in fact, they both independently affect the phenomenon in question. In this case, the relevant phenomenon is the likelihood that someone will be a current user of mental health services. Many people sometimes experience one or more of the following: finding it hard to look after themselves, feeling desperate, confused, or disoriented, hearing voices, and/or thinking suspicious or paranoid thoughts. Contrary to what clinicians have traditionally believed, there is evidence that these experiences are often unrelated to each other (Vázquez-Barquero, Lastra, Cuesta Nuñez, Herrera Castanedo, & Dunn, 1996). Those who experience only one or two of these problems are unlikely to seek help from services. By contrast, those who experience several of them, repeatedly and to a severe degree may well need significant help over a long period, come into contact with many clinicians, and receive a schizophrenia diagnosis (Cohen & Cohen, 1984; Pitt, Kilbride, Nothard, Welford, & Morrison, 2007; Ronald et al., 2014). This naturally contributes to a possible impression on the part of clinicians that people who have one of these experiences (e.g., hearing voices) also tend to have some of the others, to be very distressed, and to have ongoing problems—that is, to fit the common conception of "schizophrenia."

Another possible contributing factor is the undeniable vested interests at stake. Much of the mental health industry, both in terms of clinical services, their suppliers (e.g., the pharmaceutical companies), and research is predicated on the idea of "mental illness," diagnosed by experts and treated with the industry's products. Professional groups and pharmaceutical companies both profit hugely from the idea of schizophrenia (Whitaker & Cosgrove, 2015). The public and journalists naturally rely on the mental health industry for their information, and indeed much public information about "schizophrenia" is provided or sponsored by pharmaceutical companies, medical organizations or pressure groups. Typical statements include "schizophrenia is a devastating brain disorder . . ." (National Alliance for the Mentally Ill, n.d.) or "schizophrenia is a chronic brain disorder" (APA, 2013) or "schizophrenia is categorized as a brain disease, not a psychological disorder" (University of Maryland Medical Center, n.d.).

The processes involved are complex, both in academia and in the popular imagination. A fuller examination is beyond the scope of this article. The interested reader is pointed to work by Mary Boyle (e.g., Boyle, 2002), Diana Rose (e.g., Rose, 2008), and David Pilgrim (e.g., Pilgrim, 2013) among others.

Signs of Change?

The BPS (2014) *Understanding Psychosis and Schizophrenia* report generated considerable media coverage, links to some of which (e.g., Allan, 2014; BBC, 2014a, 2014b; Luhrmann, 2015) can be found on the report's webpage, www.understandingpsychosis.net. Most was extremely positive, although as expected, there were also some trenchant comments from those advocating a more traditional, medicalized understanding of schizophrenia. In the United Kingdom, the coordinating editor (AC) was interviewed on the main national radio news program, BBC Radio 4's *Today* (BBC, 2014b) and the same network also covered the launch in its mental health slot "All in the Mind" (BBC, 2014a). In the print media, the daily broadsheet *The Guardian* ran two major comment pieces (Allan, 2014; Freeman & Freeman, 2014).

In the United States, the *New York Times* reported favorably on the BPS report (Luhrmann, 2015) with an article titled "Redefining Mental Illness," which provoked Jeffrey Lieberman, former President of the APA, to don his white coat and post a personal blog titled "What Does the New York Times Have Against Psychiatry?" (Lieberman, 2015). In the blog he criticized not only the *New York Times* article but also the original BPS report (we covered this subplot in our previous paper [Kinderman, Alsopp & Cooke, 2017]).

Recent Developments in the United Kingdom

There are some indications that policy in UK mental health organizations is responding to the increasing scientific concern about the problems with psychiatric diagnosis in general and "psychotic" diagnoses in particular. Recent high-profile reports (e.g., Rethink/The Schizophrenia Commission, 2012) have recommended caution. Some have called for the complete abandonment of diagnosis (e.g., BPS, 2011; BPS DCP, 2013).

One example was the report of the "Schizophrenia Commission" in 2012 (Rethink Mental Illness/Schizophrenia Commission, 2012). The Commission was set up by a relatively traditional UK mental health charity, Rethink Mental Illness. The Commission had a mainstream, high-profile membership and was chaired by eminent psychiatrist Professor Sir Robin Murray. Perhaps surprisingly in view of this, and despite its name, the Commission's concluding recommendations included "extreme caution in making a diagnosis of schizophrenia" (p. 7). The reason given was that "it can generate stigma and unwarranted pessimism" (p. 7). In a recent article called "The End of Mental Illness Thinking?" the current Chair of the BPS DCP, Richard Pemberton (Pemberton & Wainwright, 2014), suggested that

> The impetus for a complete overhaul of existing thinking comes from the manifestly poor performance of mental health services in which those with serious mental health problems have reduced life expectancy. It advocates using the advances in our understanding of the psychological, social and physical mechanisms that underpin psychological wellbeing and mental distress, and rejecting the disease model of mental distress as part of an outdated paradigm. (p. 216)

Alternatives to the Schizophrenia Diagnosis

The issue of possible alternatives to diagnosis, both in general and in case of "schizophrenia" in particular is a complex one that has been explored elsewhere in these special issues, for example, by Lucy Johnstone (2017) and in our own previous paper (Kinderman, Alsopp & Cooke, 2017). It was also the subject of the "Global Summit on Diagnostic Alternatives" (see, e.g., Raskin, 2014) and is the focus of ongoing work within the BPS DCP (e.g., Cromby, 2007; BPS DCP, 2014), which has established a "Beyond Psychiatric Diagnosis" committee (BPS DCP, 2014). Any alternatives need to address the different functions currently performed (albeit imperfectly) by diagnosis, for example, naming, explaining, and classifying. Briefly, our own suggestions for the former would take as a starting point a phenomenological approach: a description of the person's own experience, wherever possible in their own words, for example, "hearing voices," without imposing a particular interpretation (see, e.g., Kinderman et al., 2013). This is the approach adopted by the Hearing Voices Network (see http://www.hearing-voices.org/) and by an important new textbook of what has often (mistakenly in our view: see Kinderman, 2016) been called "abnormal psychology" (Cromby et al., 2013). In terms of explanation, such self-descriptions can be extended by means of a collaboratively developed psychosocial formulation as outlined above. The third function, classification, is arguably a political rather than a strictly clinical one: within insurance-based health care systems like that in the United States, categories are needed to determine decisions about allocation of resources. They are less necessary within socialized healthcare systems like the one in the United Kingdom, where clinicians are able to allocate resources based on individual clinical need.

We would like to leave the last word to someone who has been personally affected by issues raised here. The first author's departmental blog site "Discursive of Tunbridge Wells" (https://blogs.canterbury.ac.uk/discursive/) carries pieces written by service users. Reflecting on her reaction to the widespread debate about diagnosis and the idea of mental illness provoked by the publication of *DSM-5*, one contributor wrote,

> My family has been shamed and defamed by psychiatric diagnosis. Our lives, historical and present, are forever affected by it. We have felt different. We have felt defective and unacceptable. We felt that our genes were inadequate and shouldn't be reproduced. We felt that our diagnoses had to be hidden because others might think us dangerous or unpredictable. At times, we felt so 'other' that we had to hide our experiences even from one another. We lived with secrets and silence that reached into every corner of our lives. (Thomas, 2013)

The author continues,

> If psychologists are right that the primary causes of mental illness are psychosocial rather than biological, my family narrative can be re-written. We can emerge from our closets of shame and take our rightful place on the continuum of acceptable human experience.

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"It doesn't mean I'm useless": how do young people experiencing psychosis contribute to their families and why are contributions sometimes overlooked?

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ABSTRACT

Purpose: Psychosis is often seen as a "burden" on families and affected individuals frequently hold a negative view of themselves. This study explored the ways in which young adults who have experienced first-episode psychosis make a positive contribution within their families. *Methods*: Fifteen participants (seven young people with experience of psychosis and eight relatives) were interviewed separately. Their accounts were analysed using grounded theory methodology. *Results*: For many individuals, their experience had led to a catastrophic redefinition of their identity. However, they continued to contribute significantly both within their families and within their wider communities. The redefinition of identity sometimes appeared to create a "perceptual filter" whereby both the person themselves and family members overlooked or minimised their contribution, focusing instead on being alert to signs of psychosis or illness. *Conclusions*: Shame and a focus on symptoms rather than achievements and contributions can significantly limit opportunities, expectations and movement beyond an illness identity. It is important for clinicians to be aware of this and to help young people and their families to notice and value positive contribution, and so promote recovery, well-being and post-traumatic growth.

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Introduction

For the majority of those who experience psychosis, the first episode ("first-episode psychosis" or FEP) occurs in adolescence or "emerging adulthood" (World Health Organisation, 2004). This period often represents a time of instability and identity formation when the young person explores possible future roles and lifestyles. Challenges and opportunities encountered in the course of such critical transitions may shape life goals and aspirations, and the person's enduring sense of self (Little, Philips, & Salmela-Aro, 2007).

A psychotic episode is often a major, traumatic life event both for the individual him/herself and his/her family, leading to both parties actively re-orienting goals and expectancies (Slade, 2009). The way that individuals, families and society make sense of and respond to experiences of psychosis may have significant consequences for the person's forming identity and future wellbeing.

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A number of authors (e.g. Birchwood, Fowler, & Jackson, 2000) have suggested that by framing psychosis as "severe and enduring illness", services have historically overlooked the possibility that a first episode may constitute a critical period in determining future outcomes. Birchwood and colleagues recommend that services should focus on preventing secondary disability or a future "spoilt identity" (Goffman, 1990).

A member being diagnosed with "serious mental illness" has been described as a "pivotal, catastrophic and cumulative" stress for a family (Lukens, Thorning, & Lohrer, 2004, p. 489). There is a large literature on "carer burden" (e.g. Kuipers & Bebbington, 2005). Notwithstanding the undoubted strains of caring (Cooke, 2017), it is possible that a focus on "burden" may contribute to poor self-image amongst people who have experienced psychosis (Ahmed & Boisvert, 2006). It may also hinder the development of an evidence base regarding their strengths and contributions.

A growing body of research suggests that there can be positive as well as negative aspects to psychotic experiences. For example, some people view their crisis as transformative (Cooke & Brett, submitted) and there is increasing interest in the idea of post-traumatic growth (Zoellner & Maercker, 2006). Individuals with a diagnosis of schizophrenia have been shown to make a positive contribution to their families (see Coldwell, Meddings, & Camic, 2010). A contribution is defined as any action which has a positive impact on the family, be it practical (e.g. childcare) or emotional (e.g. support). However, the available literature has a number of limitations. Few studies include a service user perspective and only one has undertaken qualitative exploration of the nature of contributions (Coldwell et al., 2010). Participants in the latter study had ongoing difficulties, and its relevance to individuals who are experiencing psychosis for the first (and perhaps only) time is unclear. It is possible that such individuals make an even greater contribution. This also seems a critical period to study given that identities and future trajectories are being shaped (NIMHE, 2004). The development of an evidence base relating to positive contributions may help counter negative stereotypes and protect young people's developing self-concept and self-esteem (Cooke, 2017).

The aims of the current grounded theory study were therefore to:

(1) Explore individuals' and their families' perceptions of the extent to which positive contributions are lost or preserved during, and following, a first psychotic crisis
(2) Explore the processes by which positive contributions are acknowledged, maintained and increased
(3) Develop an exploratory model explaining the relationships between these factors.

Methodology

Participants

Fifteen participants were interviewed. Participants had either experienced FEP ("individuals"/"young people") or were a family member or partner of someone who had ("relatives") (Table 1). Individuals were recruited through Early Intervention in Psychosis (EIP) services in two NHS Trusts and had used those services for between 6 and 24 months. Services considered young people to be stable, although most were experiencing ongoing symptoms. All had had at least one hospital admission and/or been subject to compulsory treatment. In order to preserve anonymity, quotations will indicate only whether the participant was an individual or relative, and references to individuals will use the female gender. Table 1 summarises participant characteristics.

Ethical and R&D approval

Ethical approval for the project was obtained from an NHS research ethics board. Research and Development approval for the project was obtained from two NHS trusts.

Table 1. Participant characteristics.

Name[a]	Age	Gender	Status	Accommodation	Employment	Diagnosis	Frequency of contact
Margie[c]	16–20	Female	Individual	Living with partner	Student	Depression with Psychosis	Several times a day
Caroline[c]	16–20	Female	Individual	Living in family Home, with Susie and David	Volunteer	PTSD with Psychosis	Several times a day
Natalie[c]	16–20	Female	Individual	Living with partner	Student	PTSD with Psychosis	Several times a day
Janet[c]	26–30	Female	Individual	Living independently	Unemployed	Psychosis	At least once a day
Hannah[b]	16–20	Female	Individual	Living in family Home	Part-time	Bi-polar with Psychosis	Several times a day
Susan[c]	21–25	Female	Individual	Living with partner	Full-time and Student	Psychosis	At least once a day
Simon	16–20	Male	Individual	Living in family Home with Ruth	Unemployed	Schizophrenia	Several times a day
Sally	21–25	Female	Margie's Partner	Living with partner	NA	NA	Several times a day
Melissa	46–50	Female	Natalie's Mother	Not living with Natalie	NA	NA	Several times a day
Susie	46–50	Female	Caroline's Mother	Living in family Home with Caroline	NA	NA	Several times a day
David	36–40	Male	Caroline's Father	Living in family Home with Caroline	NA	NA	Several times a day
Robin	46–50	Female	Janet's Mother	Not living with Janet	NA	NA	At least once a day
Elaine	56–60	Female	Susan's Mother	Not living with Susan	NA	NA	At least once a day
Ray	61–65	Male	Susan's Father	Not living with Susan	NA	NA	At least once a week
Ruth	36–40	Female	Simon's Mother	Living in family Home with Simon	NA	NA	Several times a day

[a] Pseudonyms
[b] Singleton
[c] Experienced positive symptoms in the month before interview.

Procedure

Service users who met study criteria were approached by a member of EIP staff. Interested participants gave consent for the staff member to pass on their contact details. Participants gave written consent.

Data were collected through semi-structured interviews of 40–90 minutes' duration which were recorded and transcribed.

Analysis

The data were analysed using standard procedures for Grounded Theory (GT) (Charmaz, 2006). Reflexive diaries, memos and auditing were used to ensure the quality and reliability of the analysis. (These are available, together with the interview schedules and further details of methodology and analysis in Allman, 2011). Through the use of "bracketing", the research team periodically reviewed how pre-existing beliefs and commitments might be influencing the emerging model (Willig, 2008). Credibility of the analysis was evaluated using Yardley's (2000) guidelines.

Epistemological position

As is common in Grounded Theory studies (Charmaz, 2006), the epistemological position adopted in the study was one of critical realism (Bhaskar, 2013). This stance acknowledges that the statements made by the participants are just that, statements, and can only reflect participants' perceptions rather than being a direct index of the processes they are describing. However, unlike its more radical cousin social constructionism, critical realism sees these statements as often containing valuable information about the "real world" – the phenomena being described – albeit seen though a particular lens. Accordingly, the assumption here is that participant statements do reflect, albeit imperfectly, the nature of the young people's *actual* contribution, as well as participant beliefs and assumptions. The interview method has the advantage not only of being more practical than sending researchers directly into people's homes, but also of capturing people's reflections on, as well their accounts of, events.

Results

Summary

All participants confirmed that the young people made extensive positive contributions to their families. However, such acts frequently appeared to go unnoticed. The opportunity for contribution appeared to be shaped by individuals' self-concept and also by the family's view of them, particularly of their ability to manage difficulties. However, those individuals who contributed most significantly were not necessarily seen as more able to cope. The extent to which contributions were noticed and valued appeared to depend largely on the context, on the relationships between the individuals concerned, and on the extent to which the person viewed him/herself, or the family viewed him/her through what might be called a "perceptual filter" whereby the psychosis came to dominate their identity.

These processes are summarised in Table 2 and will now be explained in more detail, with examples.

Table 2. Themes in young people's and relatives' accounts of their contributions to their families following first-episode psychosis.

Overarching themes	Themes
Contribution	Practical support Emotional support Reciprocal exchange Family & personal enhancement
Changed identity	Psychosis-as-self Acting normal Personal growth
Managing difficulties & expectations	Managing difficulties Perceived ability to cope
Noticing &valuing	Perceptual filter Relationships and context

Contribution

Most young people and their relatives considered them to be contributing as much as or more than their peers:

> I think already she does far more than most teenagers. (Relative)
>
> She's still a good role model for her sister … a better person than a lot of teenagers that don't have psychosis. (Relative)
>
> She'll do the ironing, or clear up … her brother wouldn't do, but she would without being asked. (Relative)

While contributions reduced during crises, they rarely disappeared completely. Contributions appeared to take four main forms:

Practical support

Individuals were described as contributing in numerous practical ways including care-giving, financial support, housework, cooking and sharing their particular skills.

> I do the housework with my mum, every day .... I sometimes cook dinner ... I help around the house a lot and do a lot of sewing and craft things. (Individual)

Emotional support

Most interviews highlighted the emotional support that individuals gave to other family members:

> She's somebody who I can trust, who I can rely on, who I can talk to ... if I feel down myself she's there .... She goes to a lot of effort to let you know that you, yourself, are valued and loved. (Relative)

Reciprocal exchange

In most cases, help and support was mutual. Three of the young people were themselves also long-term carers.

> I've always got a feeling that they can rely on me. (Individual)

Personal and family enhancement

Whist all families had found the experience stressful, all felt they had also benefited. Examples included becoming closer as a family, discovering strengths, gaining knowledge, empathy, skills and self-worth, recognising the need to make changes and coming to value and appreciate life more.

> Other people who haven't been through something quite as severe as this, don't quite know how they would cope with it. But we know. (Relative)

Changed identity

Most participants felt that their experiences had changed the way the young person viewed and felt about themselves. These changes fell into three main categories, labelled respectively as "psychosis-as-self", "acting normal" and "personal growth".

Psychosis-as-self

Even though things often returned much to normal after a crisis, the experience and being labelled "psychotic" often appeared to lead to a catastrophic redefinition of the young person's identity. Many described feeling defective, abnormal and shameful, and some feared that they might become violent. This appeared to be related to social stereotypes of psychosis (Cooke, 2008):

> The name doesn't help .... when I got told, I just thought I'm a psycho ... you just think of someone that goes killing people and .... does crazy things. (Individual)

The extent to which this redefinition of identity was experienced as catastrophic appeared to be related to the degree of prejudice or discrimination that people experienced or expected from others. Both individuals and relatives indicated that they frequently experienced discrimination and that this limited potential opportunities to contribute within their communities.

> My manager .... said in front of me "Don't ask [name] because she's crazy" and then no one asked me my opinion. (Individual, who shortly afterwards left her job)

Stigma and shame sometimes appeared to overshadow contribution and minimise any positive effect it might have on well-being and identity. Even where individuals knew they made a positive contribution, they often held a negative view of themselves, and social stereotypes also appeared to affect the way their loved ones viewed them.

> Just because some people are ill, it doesn't mean that they're useless ... but then I would be like "... you're weird". (Individual)

Acting normal

Fear of discrimination or of being judged or stereotyped led to enormous pressure to appear "normal". Some young people hid their experiences or avoided showing any strong emotion. This sense of needing to put on a front often reinforced individuals' sense of difference. One participant used the metaphor of "coming out":

> I think it's more detrimental to a person to hide who they are because then you get really confused about who you actually are. Cause there's the person you're being, and the person you are … do the actions make the person? … If you don't know who you are, they're [others] not going to know. (Individual)

Personal growth

Despite these challenges, all but one of the interviewees felt that the individual had grown and developed through their experience. Participants described increased maturity, empathy, responsibility, strength, resilience, a better sense of humour and a better appreciation of life. Whilst these were sometimes attributed to the normal course of maturation, many participants felt that the experience of psychosis had been highly significant.

> If I can get through that and having them horrible experiences every day, all day, then I can do anything. (Individual)

Managing difficulties and expectations

The level of contribution was influenced not only by the nature and extent of the person's ongoing difficulties but by their own and others' expectations of their ability to cope. Whilst there was an increase over time in both expected and actual contributions, this did not automatically alter how the individual was viewed by themselves or others.

Managing difficulties

Whilst young people who were still experiencing intense symptoms often found it harder to contribute to family life, this changed as they found ways to manage their difficulties.

> The voices weren't controlling me enough to hide away, so I was able to go look after my Nan. (Individual)

Perceived ability to cope

Individuals and relatives often feared that particular activities might be too stressful for the young person. Especially where he/she had attempted suicide or relatives had feared "losing" them to madness, both parties tended to err on the side of caution.

Participants described the tension between over-protectiveness and expecting too much. Two relatives used the analogy of "giving some rope":

> I gave her a bit of rope, because I had to … I couldn't have wrapped her up in cotton wool for the rest of her life. (Relative)

Noticing and valuing

Interestingly, it was often only in the course of the interviews, as people described the various contributions that the young person made, that it became clear to them just how much he or she did. At the beginning, many young people and relatives had stated that they were contributing little. It appeared that even when contribution was substantial, it often went unnoticed and therefore largely unvalued.

Perceptual filter

For some participants – both young people and relatives – there appeared to be a kind of perceptual filter, which led them to focus on the support received rather than the contribution made by the young person. Participants sometimes appeared to take acts of contribution for granted rather than viewing them as such. For example, one young person was a carer for an elderly relative, but neither they nor their relatives mentioned this when asked directly about their contributions. At the extreme, some individuals considered that they contributed nothing at all.

> I don't do anything, my mum just does everything for me, I just take. (Individual who was a carer for a physically disabled sibling)

This often appeared to relate to the degree to which, for the speaker, the individual's identity had been "catastrophically redefined".

> When I read your form …. I was really worried because it said what positive effects does [individual] have? And I thought "Oh my God, she's got psychosis … I don't know that there is anything positive". (Relative of above individual)

Some young people felt that aspects of contribution and growth had arisen directly out of the psychotic experiences themselves. However, the pain that the crisis had caused them and their families often made it hard to acknowledge the positives:

> … Whenever I think of it, I just think how it's ruined my life … So it's really hard to think of the good stuff …. I know there is, but it's really hard even saying it because then I feel like I'm betraying myself because I've just come through a year of hell and then I'm saying "oh there's good stuff," and there shouldn't be. (Individual)

Relationships and context

Changes in relationships or context were important in creating opportunities for, or highlighting, contribution:

> I watched her with the adults at this centre [charity where the individual was volunteering], she was … very mature with them, very well organised, very caring and she seems to be able to sort of change herself …. within a different environment. (Relative)

Even when there was a clear awareness of acts of contribution, the value attributed to such acts was dependent on context. For example, if participants were focused on a particular goal (e.g. being symptom-free or gaining employment), they tended only to value contributions which related to that. Another important aspect of context was simply the opportunity to reflect on contributions and on progress more generally. Some participants commented that the interviews themselves had been helpful in this regard:

> Just, talking about it …. with you …. shows me … how far we've come … And this is the first time I've complimented myself, tonight, and I was just like "wow". (Individual)

Discussion

The current study is the first to focus on the positive contribution made to their families by young people who have experienced psychosis. It is a small, qualitative study and so any conclusions can of course only be tentative. Nevertheless, in these families at least, it appeared that individuals with FEP were able to, and regularly did, make a significant contribution within not only their families but also their communities. Indeed, many were described as contributing equivalently to, or more than, peers. However, it appeared that *even* when contribution was substantial, it often went unnoticed and therefore largely unvalued. This may constitute a self-fulfilling prophecy: the failure to notice or reinforce contribution may lead over time to its diminution. A "perceptual filter" often appeared to be in operation whereby contribution went unnoticed because attention was focused elsewhere, for example on symptoms or on catastrophic fears of losing oneself or one's loved one to madness and a "mental patient" identity. This is consistent with the findings of Markowitz, Angell, and Greenberg (2011) who suggested that stigmatised self-appraisal in individuals diagnosed with schizophrenia may be related to poorer long-term outcomes.

Expectations appeared to play a key role in determining whether contributions were noticed, reflecting Raune, Kuipers, and Bebbington's (2004) distinction between objective and subjective burden. Expectations seemed to act as a filter, focusing attention on problems and risking keeping families stuck in an "illness ideology" (Maddux, 2008).

Significantly, the current findings contrast with Charmaz (2002) findings relating to in self-concept in severe physical illness, which suggested that it does not change immediately upon diagnosis but rather gradually through iterative feedback. In contrast, both individuals and family members indicated that being diagnosed with psychosis had led to an *immediate* and, for many, *catastrophic* change in self-concept – and in how others saw them – changing their identity to that of a "mental patient" (Cooke, 2008). Significantly, it appears that the strength of this new identity can create a perceptual filter or "reverse-halo effect" (Nisbett & Wilson, 1977), which makes it resistant to being changed by subsequent information. While all individuals in the current study appeared to be engaged in regular acts of contribution, it was interesting that at the start of the interviews, many young people and relatives had begun by stating that the individual was doing little to support his or her family. It was only as the interviews progressed, and as they named the various things that they young person was doing, that they realised that this was not the case.

Clinical implications

The damaging effects of an "illness identity"

Tracy Emin's work "My Bed" clearly exemplifies that the perceived value of an object depends to a large extent on its context (see e.g. Cherry, 2002). In a particular context, a detritus-covered bed is transformed from an object of shame to high art. Duchamp's "Fountain" does the same with a urinal (see e.g. Mundy, 2015). Conversely, the challenging nature of psychotic experiences, combined with stigma of the label, can create a context which overshadows any other expressions of identity (Lally, 1989). If the self becomes synonymous with psychosis, acts which would normally be ascribed value may be viewed as irrelevant, and may therefore make little difference to how the individual is viewed or views him/herself. This may be one of the processes by which a "spoiled identity" (Goffman, 1990) is maintained.

In addition to being viewed as irrelevant, positive acts of contribution may be attributed to external factors rather than to the individual. For example, in the current study many individuals and relatives attributed an individual's contribution to changes in medication/therapy/service input. These may of course have played an important role for some, but it is the way that participants' accounts often appeared to privilege them that is of interest here. An ironic process appeared to occur whereby increased contribution, when framed in relation to improved management of "symptoms", located agency outside the individual and confirmed his or her identity as a "psychiatric patient" (Maddux, 2008).

The importance of asking about positive contributions

Both the current findings and those of Coldwell et al. (2010) indicate that simply asking about positive contribution may help to counteract this perceptual filter. This suggests that it is important that workers routinely ask about it.

Recognition of people's contribution might help reduce symptoms

Several studies have suggested that the more negative one's sense of self, the more negative the content of hallucinations (e.g. Garety, Kuipers, Fowler, Freeman, & Bebbington, 2001). Additionally, Garety et al. (2001) suggest that the strength with which psychotic beliefs are held is related to the extent to which they fit with the person's self-concept. Recognising the value and worth of acts of contribution may therefore not only be important in its own right but may lead to symptomatic improvement if the individual starts to relate to himself or herself more positively.

Recognition of personal agency and the potential for recovery can aid post-traumatic growth after crises

There is growing interest in the idea that psychotic crises, whilst distressing, can also be "transformational" in the sense of leading to growth and development (Cooke & Brett, submitted). In general, positive change following traumatic events is heavily influenced by the degree of control that the person perceived themselves to have had in the traumatic situation, even if this control was illusory

(Zoellner & Maercker, 2006). Therefore, neglecting personal resilience and locating agency outside the individual (e.g. in family "carers" [Murray, 2014] or services) may reduce the potential for such growth (Tedeschi & Calhoun, 2004) following psychotic crises.

Recognition of agency and abilities may help families

Modifying perceptions of agency may also modify the perceived demands of care-giving. The cognitive-mediational stress theory (Lazarus & Folkman, 1984) suggests that the affective response to a demand is based on an appraisal of the nature of the demand in relation to one's belief that one can meet it ("self-efficacy"). If relatives perceive themselves as wholly responsible for their loved one's mental health, they are more likely to appraise this situation as being beyond their capacity. Services could perhaps be more cautious in ascribing the term "carer" in this regard (Slade, 2009). Conversely, increasing awareness of a loved one's agency and abilities may decrease the perceived emotional strain. Similarly, access to support and materials (e.g. Cooke, 2017) which stress the possibilities for recovery and growth could make a significant difference both for people who have experienced a psychotic episode and for their families.

Limitations

A number of factors limit the conclusions that can be drawn from this study. Firstly, the sample was small: in order for the findings to be generalisable, a larger study would be needed. Secondly, it was relatively homogeneous: all participants were White British, most were female and all were in regular contact with family or partners. Their experiences may not represent those of, for example, individuals from other ethnic backgrounds or who live alone. It is also possible that the sample was self-selected in the sense that individuals who make less frequent contributions, or their families, might have been less motivated to take part. However, notably, prior to interview four of the 15 participants expressly stated that either they or their family member did not contribute at all. Practical constraints prevented theoretical sampling in this regard (i.e. specifically interviewing individuals who differed in these respects) and this would be interesting to explore in future studies.

Future research

The findings suggest it would be useful to explore the relationship between contribution and recovery in FEP. An obvious first step would be to carry out a larger-scale study. Research with participants from different backgrounds or less family contact would also be useful, together with clinician beliefs about positive contribution. It is possible that the difficulties experienced in recruitment were partly the result of such beliefs. Services frequently reported difficulty identifying possible participants because care-coordinators viewed their clients as not contributing to their families. This is significant as whilst hope is known to be important in recovery (Leamy, Bird, Le Boutillier, Williams, & Slade, 2011) services may be communicating a message of hopelessness. Finally, longitudinal research would help to clarify the processes involved and the direction of causality.

Conclusion

The results suggest that while individuals with FEP can and many regularly do contribute to their families, such contributions may not always be noticed or valued. The catastrophic redefinition of identity that occurs upon being labelled psychotic, together with the effects on both service users and their families of current social narratives about psychosis, often appears to direct attention away from the positive contributions which individuals make. This in turn may reduce opportunities for them to occur and be incorporated into the individual's identity. If both services and families are careful to notice and value contribution, this may reduce stress and enhance wellbeing for all concerned.

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9

WHERE NEXT FOR CBT AND PSYCHOSIS?

Caroline Cupitt and Anne Cooke

The arrival of the third wave of CBT has been a gradual process and its status remains contested. Arguably it has given greater attention to a person's relationship to their experience and the processes which contribute to distress. However, some (e.g., Hofmann et al., 2010) have questioned whether this is truly a new wave, ~~suggesting~~ that the key elements can in fact already be found in the broader family of CBT approaches. Do the approaches described in this book collectively merit the term 'third wave'?

What's new (and what's not)?

This book has included meta-cognition as the starting point for third wave approaches. However, whether or not it should be seen as part of the third wave is a matter of some debate. Hayes et al. (2006) consider it such, specifically mentioning Wells' (2000) Meta-Cognitive Therapy (MCT). However, Wells himself does not, considering MCT to be an extension of, but part of, traditional CBT (Hofmann & Asmundson, 2008). He has a point, since CBT has for a long time encouraged people to notice the effect of their thinking and in particular the counterproductive effects of thought suppression. Traditional CBT has also acknowledged the importance of higher-order meanings, sometimes called modes or schemas, which organise our relationship to individual thoughts or events. For example, as early as 1993 John Teasdale suggested that alongside any direct gains from challenging negative thoughts in traditional CBT, 'it may be that the very action of attempting to deal with negative thoughts, in common with other active coping procedures, leads to the synthesis of schematic models related to taking control' (Teasdale, 1993). Arguably CBT has never simply been a mechanistic approach to changing the content of thoughts, as Hayes (e.g., 2004) appears to imply.

Acceptance and Commitment Therapy (ACT) has its roots in radical behaviourism, albeit with a welcome added emphasis on internal events and their context. Hayes (2004) states that, 'ACT is neither from the first wave of behavior therapy nor the second, although it builds upon both' (p. 645). However, despite its distinctive theoretical justification being based on Relational Frame Theory, it could be argued that it ends up in a similar place. For example, a central focus is the role of experiential avoidance. Tackling avoidance is hardly a new focus for CBT: indeed exposure is one of the most effective elements of the first wave of Behaviour Therapy. Although Hayes (2004) claims that, 'acceptance and willingness in ACT leads to a different kind of exposure: experiencing actively and fully in the present' (p. 656), no doubt adherents of the first wave would argue that they have always asked that people fully expose themselves to their feared stimulus (e.g., Marks, 1979). What ACT appears to add is a broader conceptualisation of that stimulus to include present moment experience.

Likewise it could be argued that the ACT term 'cognitive fusion' describes the same rapid, automatic thinking characterised in the second wave as 'negative automatic thoughts' and from which the therapy aims to help the individual disengage. In traditional CBT this is done by promoting awareness, writing down thoughts and then reviewing their content and effects. The ACT idea of 'defusion' appears similar: people are invited to approach their thinking in a less literal way and not to act on particular cognitions. Thus whilst the content is not directly challenged, a person's relationship to it is changed. This is clearly helpful, but is it a distinctively new approach? Having received traditional CBT someone may also continue to experience the same negative automatic thoughts, but no longer believe or be swayed by them as before. One could therefore argue that what ACT brings is a refinement of traditional models, rather than an innovation (Greenwood, 2017). However, by expressing the task in new terms it has certainly captured the interest of a new generation of therapists.

Eastern influences

A common feature of ACT, mindfulness approaches, and Compassion-Focused Therapy (CFT) is that they all look to Eastern psychologies for inspiration. Eastern traditions such as Buddhism are founded on individual exploration of mental phenomena, rather than scientific empiricism, and as such bring an understanding of subjective cognitive process to CBT. However, the integration of these ideas is at an early stage and it is not always clear what is meant when cross-over terms are used. For example, within ACT there is an emphasis on self as context, described as a transcendent self which is 'a no-thing' (Hayes, 2004, p. 656). This appears to draw on ~~Buddhist ideas~~ of non-self (Sanskrit: *anatman*), which refers to the experience of the absence of a permanent and stable self, but at the same time is described as a safe place from which to experience difficult content. From a Buddhist perspective this 'safe place' is perhaps more likely to be a refinement of the ordinary constructed self; perhaps a version of 'the watcher' or observer of thoughts rather than non-self (Trungpa, 1992). It is therefore hard to be sure what is meant by the ACT notion of 'a transcendent self'. Is it more than the idea that it is possible to observe one's thinking?

Mindfulness approaches can also find themselves in some confusion about the difference between Eastern and Western conceptions of the practice. For example, in many Buddhist traditions, such as Zen, meditation to merely improve one's health is viewed as the shallowest form of the practice. Such a mundane goal is very much secondary to the main purpose of Buddhist meditation, which would always be spiritual realisation. In transposing mindfulness into CBT, this philosophy underpinning the technique has been lost, including the teaching on non-self. As Grossman (2011) points out, the goal of the practice then becomes unclear: is it just about increasing wellbeing by means of attentiveness in everyday life, or something more profound? Without clarity about the nature of self in relation to experience, it is difficult to know.

Perhaps CFT has given the most emphasis to its Eastern links, and in this case they primarily come from Mahayana Buddhism. Paul Gilbert has co-authored books with Tibetan Tulkus (Buddhist teachers) and quotes the Dalai Lama in his writing (e.g., Gilbert, 2005). However, despite the references, the extent to which Buddhist teachings have actually influenced the approach is unclear. Buddhism after all does not own exclusive rights to the promotion of compassion, which has been an important part of all world religions and indeed an important part of ~~P~~sychotherapy for a long time. It is also a word which can be used very differently in different contexts. When CFT uses the term, it appears to be referring to an active engagement with difficult experience at an emotional level. This focus on emotion stems from the influence of evolutionary psychology and attachment theory, and is an important contribution to the practice of CBT, especially in the context of psychosis. Traditional CBT tended to emphasise appraisal of voices and re-evaluating unusual beliefs, without much attention to emotion except in relation to triggering events. More recently both CFT and ACT have stimulated interest in how our emotional responses can become part of the problem, particularly if we seek to suppress or avoid them. Skills in accepting and soothing emotional distress are therefore now developing an important place in the repertoire of a CBT therapist working with an experience of psychosis (see Chapter 2).

Universal processes

The therapeutic developments included in this book all pay more attention to process than traditional CBT, which was arguably more focused on the content of cognition. In making this shift away from content, CBT is beginning to ~~identify~~ universal processes which underlie distress. For example, the Method of Levels (~~MoL~~), although clearly a meta-cognitive form of therapy, is different in making its focus the control of perceptual experience rather than behaviour. However, in practice a session may look rather similar to CBT: for example, the therapist redirects awareness using techniques not dissimilar to Socratic questioning. Implicit within it is the normalising assumption that everyone experiences conflict and emotional distress from time to time and that everyone has the capacity to reorganise psychologically to resolve this. This conception of a universal process may be more significant than it first appears.

Part of the underlying philosophy of ACT is an acceptance that suffering is inherent to life. This has allowed the therapy to avoid getting too involved with illness labels, which has both contributed to a normalising stance and encouraged a trans-diagnostic approach. Both CFT and ~~MoL~~ also claim to address universal psychological processes and have quickly found application across many different forms of distress. These new forms of therapy have reawakened interest in universal psychological processes of suffering, which more symptom-focused CBT by its nature had neglected.

Does all this constitute a 'third wave' of CBT? The answer all depends on how one defines a wave. It does not appear to be a wave quite like the previous two. If this is indeed a third wave, its contribution is perhaps not to add a whole new sphere to CBT, but rather to bring out and to emphasise certain elements and present them again, this time better understood. As such it is clearly an important stage in, and vehicle for, the evolution of CBT.

Better outcomes?

As yet we do not know whether this renewed focus on underlying psychological processes actually improves outcomes. As many commentators on second wave research have found, identifying the effective elements of a CBT approach is a challenging task. Those who have tried have often suggested that the most effective elements within the second wave may be those derived from the first; for example, behavioural activation and exposure therapy (Longmore & Worrell, 2007). However, as Hofmann et al. (2010) point out, failure to demonstrate that change occurs by explicitly changing cognitions does not necessarily mean that cognitions are not the mediators of change. It may well be that cognitive processes are central to effectiveness.

There have been some meta-analyses of the effectiveness of third wave behavioural therapies (Öst, 2008), ACT (Powers et al., 2009) and mindfulness (Khoury et al., 2013). Öst criticises the rigour of Randomised Controlled Trials (RCTs) of third wave approaches and therefore finds it impossible to describe them as evidence-based. Powers et al. conclude that receiving ACT is more effective than being on a waiting list or receiving a placebo, but not more effective than established interventions such as traditional CBT. As more research has been undertaken, the American Psychological Association (2012) has designated ACT as an empirically supported therapy for psychosis with modest research support (in contrast to CBT, which they assess as having strong research support). Khoury et al. (2013) describe a meta-analysis of mindfulness interventions for psychosis and find some moderate effect sizes, but their conclusions are weakened by the heterogeneity of the trials. More recently, a systematic review of mindfulness interventions for psychosis (Aust & Bradshaw, 2017) includes a number of new clinical trials but draws similar conclusions, asking for more rigorous, larger trials to be conducted. Chadwick et al. (2016) reported results from the first RCT of Group Person-Based Cognitive Therapy (a form of mindfulness-based CBT for psychosis), which found that the most significant sustained effect was on mood. As yet, the National Institute for Health and Care Excellence (NICE) guidelines in the UK do not recommend ACT nor any other third wave approach for psychosis (NICE, 2014).

It may yet be too early to say whether evidence will emerge showing that the third wave enhances the effectiveness of more traditional CBT for psychosis. However, we are already more than ten years into many of these ideas. Thus far we can perhaps conclude that third wave approaches can achieve outcomes equal to those of more traditional CBT but that there is as yet little evidence that they produce better ones (Kahl, 2012). The question therefore remains whether the third wave really has more to offer? Indeed, for some third wave approaches (e.g., ACT) it is possible that their effectiveness rests on operant conditioning, and thus may derive from the basic behavioural components of all CBT. For example, mindfulness-based approaches are said in part to be effective because they counter the experiential avoidance which can often powerfully maintain psychological difficulties (see Chapter 4). The practice effectively requires someone to expose themselves to provoking stimuli rather as Behaviour Therapy used loop tapes, resulting in habituation of fearful responses.

Some have argued that focus on cognitive change in CBT is unnecessary because simple behavioural techniques can produce the same degree of success (Longmore & Worrell, 2007). However, of course that does not mean that for the individuals receiving behavioural interventions, cognitive change is not occurring. In the same way, it may be that the similarity of outcomes often reported between second and third wave CBT reflects the fact that the same changes are occurring, whether they are explicitly targeted or not. Seen from this perspective, what the third wave may contribute is not necessarily better outcomes, but a better understanding of how those outcomes come about.

The importance of meaning in psychosis

Third wave approaches are characterised by a focus on people's relationship to their experiences rather than the experiences themselves. In the case of psychosis, this perhaps risks losing something, namely an exploration of the meaning and possible value of the experiences. There have always been examples of people who have found meaning in the content of their psychotic experience (e.g., Campbell, 2010; Jackson et al., 2011). They may not wish to mindfully let go of that content, but (or in addition) wish to explore its relationship to their life history in order to learn from it.

With some notable exceptions (e.g., McGowan et al., 2005) there has been little research into service users' experience of CBT for psychosis or what people find most helpful about it. A study by Kilbride et al. (2013) however, is particularly helpful in being service-user led. The authors conducted in-depth interviews with nine people and identified five major themes, one of which was 'CBT as an active process of structured learning'. Participants described the value of re-evaluating psychotic experiences within the wider context of their life experiences as part of the process of formulation. Another theme related to 'improved personal understanding of both psychosis and self'. People spoke of the value of the therapy's normalisation of their experiences: '[the therapist] helped me to see that the thoughts weren't crazy, after looking at what happened' (p. 95). The authors conclude that such normalisation is of central importance in CBT for psychosis.

There are different ways to normalise psychotic experience, but here participants are clearly valuing a detailed exploration of the content in relation to life events. There appears to be some danger of losing this aspect as the focus is taken away from content and towards process. This study suggests that opportunities to explore the meaning of such experiences need to be preserved within CBT for those who want them.

~~-diagnostic approaches~~

One of the welcome features of third wave CBT is an increasing tendency to look beyond diagnosis. In the early Beckian model (Beck et al., 1979) each 'emotional disorder' had its own maladaptive cognitions, be it a fear of dying in panic attack or a fear of social embarrassment in social anxiety. Whilst this symptom-focused approach has led to important developments, it has also tended to mean that the diagnostic system itself has avoided criticism from within the CBT community. Elsewhere it has come under increasingly intense scrutiny and attracted widespread critique, particularly since the launch of DSM 5 (Kinderman et al., 2017). It is therefore refreshing that many of the third wave CBT approaches, such as ACT, are not reserved for specific diagnostic groups.

Even within the current diagnostic framework, there has been recent research on the benefits of using CBT to address common problems such as sleep or worry within the context of psychosis, with promising results. Waite et al. (2016) describe using a standard CBT intervention for insomnia (Espie, 2006) to improve sleep for people who have received a diagnosis of schizophrenia. Despite the use of the diagnostic term, this approach cuts across the Beckian idea that treatment needs to target cognitions specific to the diagnosis in order to work. Instead they find that helping people with their sleep can, 'reduce the frequency and intensity of distressing psychotic experiences and improve coping capacity' (p. 282). Such approaches do not fall into the category of the third wave, but appear to be part of a wider movement towards more trans-diagnostic CBT interventions. By their nature they also contribute to normalising the experiences of people experiencing psychosis, by suggesting that they can benefit from the same interventions as the general population.

Likewise, Freeman et al. (2015) have demonstrated that a brief worry intervention significantly reduced both worry and persecutory delusions, even though the strategies did not involve challenging the persecutory beliefs themselves but were based on a standard CBT worry-reduction intervention (Freeman & Freeman, 2013). Recipients of the intervention found the focus on worry helpful and agreed that they had this problem, giving it high face validity. Interestingly, only eight people assessed as having persecutory delusions did not have sufficient worry to be included in the study. The authors speculate that although they found significant effect sizes for persecutory delusions, potentially there could be many more benefits to be gained from reducing worry. The approach also has the advantage of being more acceptable to the many people who do not see themselves as psychotic nor wish to enter into a dialogue about their 'delusional beliefs', per se.

One striking aspect of both of these developments is the brevity of the interventions. At six to eight sessions, they are much shorter than the usual length of CBT for psychosis (which UK NICE guidelines suggest should be at least 16 sessions), and yet they appear to produce lasting change for people. This suggests that one means to empower CBT interventions for psychosis ~~is~~ to make them less condition-specific and instead target common psychological processes. This fits with what service users themselves have said about the importance of the normalisation of their experiences in therapy (Kilbride et al., 2013) and opens it up to those who do not view their problems as psychosis nor wish to accept a diagnostic label. This is a very common (Jansen et al., 2015) and understandable reaction given the current social construction of psychosis (Schomerus et al., 2014). Perhaps in the future CBT may no longer view people through the lens of diagnostic categories, and dividing CBT into branches such as CBT for psychosis will become unnecessary.

A fourth wave?

Given that we are now already many years into the development of third wave CBT, it is interesting to speculate about the future direction for CBT and of a possible fourth wave.

If the first wave took behaviour as its focus and the second cognition, the multiple strands of the third certainly suggest that as CBT matures it is becoming more able to address the complexities of mental distress. For example, it has begun to break down old divisions between psychosis and 'normality' and the binaries of diagnosis. Thus far, however, the focus of both theory and intervention remains largely at an individual level. The obvious next step is to look outside the individual to consider the effect of the social context and our relationship to it in shaping experience.

Over the last twenty years, psychological theories of psychosis in the cognitive tradition have increasingly acknowledged the importance of the social environment – the events and circumstances of people's lives, and especially of their early lives – in the aetiology and maintenance of psychosis (e.g., Bentall et al., 2012; Dillon et al., 2014; Hardy et al., 2016). Empirical studies have provided ample support. Varese et al., (2012) for example, found that experiencing multiple childhood traumas appears to give approximately the same risk of developing psychosis as smoking does for lung cancer.

This emphasis on the role of the environment has been slow to develop and is still not ubiquitous, perhaps because of fears of a return to the 'mother-blaming' theories of the 1950s and 1960s. One of the authors remembers a prominent theorist, Richard Bentall, attracting fierce criticism from clinicians and researchers in the audience at a British Association for Behavioural and Cognitive Psychotherapies (BABCP) conference in the late 1990s for suggesting that adverse early experiences within the family could play a role in the genesis as well as the maintenance of psychosis (Bentall, 1999). In the intervening years, however, their role has been increasingly acknowledged and UK NICE guidelines now suggest that services should assess for 'reactions to trauma because people with psychosis or schizophrenia are likely to have experienced previous adverse events or trauma associated with the development of the psychosis' (NICE, 2014).

Some current authors go further and now stress the need to avoid psychocentrism; that is, the excessive focus on internal, psychological factors as opposed to the social and material environment (LeBlanc & Kinsella, 2016; Rimke, 2016). In a way it could be argued that this focus on the events and circumstances of people's lives is a return to the behavioural roots of CBT in that the role of the environment (albeit often somewhat more narrowly understood) is of central importance in behavioural theory.

A related development has been an increasing acknowledgement of complexity and heterogeneity of psychotic experiences, and of the 'complex interactive dance of nature and nurture' (Kinderman, 2015) that calls for humility and for aetiological agnosticism in any particular case. In the words of the recent British Psychological Society report, to which many CBT researchers and practitioners contributed:

> The causes of a particular individual's difficulties are always complex. Our knowledge of what might have contributed, and what might help, is always tentative. Professionals need to respect and work with people's own ideas about what has contributed to their problems.
>
> (Cooke, 2017, p. 103)

Taking the emphasis on the environment even further, a third development that has been suggested (and this has been a step too far for some) is the abandonment of the idea of psychosis itself. If 'psychotic' experiences are often no more and no less than a natural reaction to traumatic events, the argument goes, then invoking the idea of mental illness or psychosis may be unhelpful and tantamount to victim blaming. For example, Johnstone (2011) suggests:

> there is growing evidence that the experiences service users report . . . are, in many cases, a natural reaction to the abuses they have been subjected to. There is abuse, and there are responses to the abuse. There is no additional 'psychosis' that needs explaining.
>
> (p. 106)

This renewed focus on understanding the role of trauma has recently become central to the development of a conceptual alternative to psychiatric diagnosis, *The Power Threat Meaning Framework* (~~Johnstone, 2017~~).

Therapeutic possibilities for a fourth wave

There are a number of implications for individual and group therapy connected to the idea of a fourth wave of CBT.

A not-knowing approach

Facilitating cognitive change where needed will remain important. However, acknowledgment of aetiological complexity, heterogeneity and indeterminacy implies the need for a 'not knowing' approach to therapy (Anderson & Goolishian, 1992) where the client is seen as the expert on their own problems, and formulation and treatment are co-constructed. In the language of ACT, therapists may need to help people to defuse from the clinical meaning of psychosis and find their own language. This may involve engaging with their values, which might, for example, include an interest in altered states of mind. At the same time, people often need support with the emotional impact of what is happening to them, especially if they have come from a background of adversity and have not come to expect a compassionate response from others.

This is a very different approach to that adopted by some of the standardised, diagnosis-driven 'treatment packages' traditionally on offer. It is likely to mean that therapists will more commonly work within belief systems that would conventionally have been labelled delusional, bringing CBT closer to approaches such as the Hearing Voices Movement.

Focus on current life circumstances

Secondly, it is likely that therapy will increasingly focus on the events and circumstances of people's lives in addition to internal, psychological factors such as attributions or people's relationship to their thoughts. There has been some criticism of third wave approaches, such as mindfulness, when used with people in difficult life circumstances; for example, poverty or homelessness. Critics argue, is it right to ask people to just notice and let go of their depressed thoughts when they have no job, little money and few prospects? Might it not be more helpful to support people to better their situation so that they can begin to look forward to the future?

Whippman for example, suggests that:

> Mindfulness . . . which on the face of it advocates paying attention to the outside world, urges it in only its most apolitical form – a 'non-judgmental awareness' of whatever is directly in front of us right this second,

> deliberately renouncing analysis, critical thinking or wider imaginative empathy. . . . But this level of self-focus has come at the expense of outward engagement. Our narrative of wellbeing has become divorced from community, social justice or wider political responsibility. . . .What we urgently need now is not inner exploration, but outward engagement. Not 'non-judgmental awareness' but critical thinking.
>
> (2017)

This criticism has become more acute as the politics of 'austerity' have increased levels of poverty and social inequality. Clinical Psychologist Masuma Rahim, for example, has written movingly about her experience of 'trying to do therapy when your patient has no food or money', suggesting, 'If basic needs haven't been met, what the hell is a bit of therapy going to do?' (Rahim, 2014).

Within ACT, for example, there is an important emphasis on activating someone's pursuit of their values. However, what ACT does not explicitly address is the very real difficulties someone might have in attempting to do so. People who have experienced psychosis are often held back by a lack of opportunity, by poverty, and by the view society takes of them and their distress. Therapy needs to be informed by this, which may mean widening the focus from thoughts and feelings to helping people with practical issues. It also suggests that therapists could usefully devote some energy to changing societal views and narratives about psychosis: this is addressed below.

The emphasis on the family and social environment also implies that family or even community-level interventions may at times be more helpful than individual approaches. In the past, family interventions have often been used alongside individual CBT. Recent developments include Open Dialogue (Lakeman, 2014), an approach to family therapy which incorporates the 'not-knowing' stance referred to above and is consistent with the recent theoretical developments in CBT described here. A large-scale trial is currently underway in the UK (Razzaque & Stockmann, 2016).

Focus on trauma

Therapy may also increasingly focus not only on the general circumstances of people's lives, but also on specific traumatic experiences. Partly this will be about being 'trauma-~~focused~~', making sensitive questions about trauma a part of every first contact with mental health services – but also providing CBT that explicitly helps people to process traumatic events from their past that may have been a large part of the reason they developed psychosis. The means to do this are already being developed within CBT (e.g., Keen et al., 2017) and the chapters of this book also contain ways to meet this challenge, in particular CFT with its focus on addressing the neuro-developmental consequences of early trauma (see Chapter 6). Many therapists still have concerns about the potential harm they may cause by directly targeting trauma in the context of psychosis. There is evidence that these barriers can be overcome with specialised training and supervision (e.g., van den Berg et al., 2016), and there is an urgent need for these to be more widely available.

Support for supporters

As mental health services move away from interventions that seek to suppress psychotic symptoms and towards a better understanding of the wider context of someone's distress, supporters trying to connect with someone in a confused and frightened state of mind need to be well-equipped themselves. 'Third wave' approaches such as mindfulness and a focus on compassion have the potential to be hugely beneficial for therapists and others trying to support people in states of extreme distress. Indeed, within the Buddhist tradition from which the movement has so often borrowed, they are more likely to be seen as useful for those in supporting roles (e.g., Podvall, 2003). There is now widespread adoption of the idea that reflective capacity is an essential aspect of professional practice and yet many of the tools used to promote it are as yet unevaluated (Mann et al., 2009). In future, CBT is likely to need to expand this repertoire and develop and evaluate new ways to sustain supporters.

Beyond therapy: A public health approach to psychosis

Prevention

Increasing appreciation of the role of the social and material environment in the genesis of psychosis leads naturally to a focus on prevention. As Read (2014) pithily summarised it, 'Why do we neglect prevention? The best way to reduce rates of psychosis would be to reduce childhood adversity'. Harper (2016) has made a cogent and well-evidenced argument for therapists also to become involved in prevention; for example, by specialising in public health. There may always be a need for therapy, but without concomitant efforts at prevention, just offering treatment to those already affected equates to 'mopping the floor faster while ignoring the source of a leak' (Marsh & Cooke, 2017). Cooke (2014) argues that psychology needs to adopt a public health approach. Drawing an analogy with the public health physicians who eliminated cholera from Western Europe in the 19th century by improving housing and drainage, she suggests that the psychological equivalents of these basic necessities might be basic safety and equality (Wilkinson & Pickett, 2009).

Of course, such criticism of the focus on individual psychological interventions, rather than addressing the events and circumstances of people's lives, is not new. Psychologists have tried before to develop approaches which recognise the social realities of people's lives (e.g., Holland, 1992; Holmes, 2010; Midlands Psychology Group, 2014; Rhodes, 2015). However, they have often been seen as the domain of community psychology rather than as part of the cognitive behavioural tradition.

The theoretical and empirical developments described here suggest that this may change over the next decade. Harper (2016) asks:

> What might a preventative intervention informed by a socially contextualised Cognitive Behaviour Therapy look like? (We) could start by going out more to where people conduct their everyday lives. . . . We could encourage more 'bottom-up' rather than expert-driven 'top-down' approaches, like supporting the development of self-help and peer support groups. And we could seek to reduce income inequality. This requires action in the political realm, not only as individual citizens but also using our knowledge and status as professionals who are familiar with this research and the pernicious effects social injustice has on the lives of those who use our services.
>
> (p. 444)

With respect to psychosis, it is good to see links being established between CBT researchers and community-/peer-led initiatives such as the Hearing Voices Network (part of the Hearing Voices Movement: www.hearing-voices.org), the Mad Studies Network (https://madstudies2014.wordpress.com) and the Paranoia Network (e.g., Psychosis Research Unit, 2016).

Changing society's whole approach to understanding psychosis

A recent survey of just over 1,000 members of London's population asked about people's understanding of psychosis (Early Intervention in Psychosis London, 2015). There was 38% agreement with the statement, 'I don't know what psychosis is, and would not recognise someone experiencing psychosis'. Despite this, most people said that they would encourage a friend or relative to seek help (78%) and nearly half were optimistic about recovery (46%). About a third (31%) thought that people could recover from psychosis without taking medication. There were differences of view between groups, with women and older people sharing a higher awareness and more empathy. People in the age range 16–24 were the most pessimistic. This is of course the age when many people experience psychosis for the first time. Many will have witnessed peers develop difficulties, which as yet have an uncertain outcome.

Perhaps the most interesting thing about this survey is the confusion surrounding the term 'psychosis', in the context of otherwise fairly positive attitudes. Like other terms such as 'schizophrenia', it has a social as well as a clinical or 'official' meaning, and is widely used in the popular media to denote evil.

The poor quality of available public information impacts not only on public attitudes but also directly on how people who experience psychosis come to see themselves and their problems. It can reduce or remove the basic safety described above which is necessary for recovery. For example, the book, *Think you're crazy? Think again* (Morrison et al., 2008), described as 'a resource book for cognitive therapy for psychosis', very helpfully explains the evidence for viewing psychosis as on a continuum with normal, healthy functioning. However, outside the world of therapy it is difficult to find anything as good. It is more likely that people's first experience is like that of Jonny Benjamin – 'I felt like I'd been given a life sentence. All I knew was what I read in the papers that people with schizophrenia are violent and incapable of recovery' (O'Hara, 2013).

Discourses which denigrate 'insanity' can function similarly to the metacognitions that we know serve to maintain other forms of psychological distress, such as anxiety. The therapeutic task is therefore both to question these beliefs and metacognitions with the individual, and also within wider society.

The effects of societal discourses regarding psychosis can be particularly toxic for those whose identities are also already devalued in other ways, for example women or people from Black and Minority Ethnic (BME) backgrounds. In a ~~recent~~ study of voices' use of gender, race and other social categories to undermine female voice-hearers, Haarmans et al. (2016) argue that current CBT models have woefully neglected the socio-political context of the phenomena. They found that almost all of the women who participated in their study experienced voice content that undermined their self-worth in specifically gendered ways. In addition, more than half of the BME women also experienced voice content that denigrated their racial identity. As women who also experienced psychosis, they were doubly or triply marginalised within society and their voices told them so repeatedly. ~~The societal discourses that construct women's worth based on their heritage, appearance or sexual purity are part of what was maintaining these women's distress.~~

Across cultures, we find that unusual experiences are either valued or labelled mad in differing ways. The fear of 'going crazy' underlies a great deal of distress, not just in psychosis but also other more common mental health problems. It is perhaps surprising therefore, that the idea of changing societal appraisals of unusual experience has not received more attention within CBT as a means to reduce individual distress. It is a natural extension of meta-cognition, as we move from considering an individual's beliefs about their thoughts to society's beliefs about the individual.

There is an urgent need for CBT therapists and researchers to provide good public information and to become involved in the public debate by writing for the public and by broadcasting and podcasting. A good example is the recent British Psychological Society report *Understanding Psychosis* (Cooke, 2017) to which many well-known CBT researchers contributed.

The normalising approach inherent to CBT is very helpful with respect to such initiatives and contrasts with the 'othering' approach, premised on the idea of an 'illness like any other', for which anti-stigma campaigns have been criticised (e.g., Cooke & Harper, 2013). It is possible that the word 'psychosis' can be reclaimed in the way that words like 'queer' have been reclaimed by the communities they were previously used to deride. An alternative point of view is that the social meaning of the word (like that of schizophrenia) is so entrenched that reclamation is unlikely and that alternative terms are needed, perhaps drawing on the Hearing Voices Movement's idea of using ordinary, rather than clinical, language and people's own preferred terms.

There is evidence that social attitudes are starting to change and become more open. This appears to result from greater knowledge and increased social contact, particularly if this is between adults, face-to-face (Corrigan et al., 2012). The engagement of people who have experienced psychosis in the task of changing societal beliefs is therefore vital. Although CBT has always identified itself as a collaborative form of therapy, the actual involvement of people with an experience of psychosis has thus far been limited. Greater involvement is the natural extension of the normalisation element already established within CBT. For the fourth wave to be successful it is now an essential component.

Conclusions

CBT has promoted the idea that psychosis is understandable in psychological terms in a similar way to anxiety or depression. More recent developments have increasingly acknowledged that psychosis is often a reaction to adverse events and circumstances. In the further evolution of CBT there is a need to validate people's reactions to adversity and be careful about language which locates problems within people, since this could undermine their efforts to cope. In addition, there is an urgent need to increase prevention – in particular addressing those events and circumstances such as child abuse which we know contribute to forms of distress such as psychosis. Finally, CBT offers a variety of techniques which could be adapted to the task of changing societal discourse about psychosis and ultimately about the origins of distress, promoting more acknowledgment of aetiological complexity.

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13

TRAINING THAT DOMESTICATES OR EDUCATION THAT LIBERATES?

Tensions and dilemmas related to teaching critical psychology in the context of UK clinical psychology training

Anne Cooke

Before taking up my current academic post, I worked as a clinical psychologist in a community mental health team in inner-city London. Partly because of that experience, I became aware of the potential for mental health services to do harm as well as good. I also observed how dominant discourses and practices socialise trainee mental health professionals from various disciplines, sometimes appearing to blind them to this potential for harm (Foucault, 1967; Newnes, 1990; Coles, Diamond, & Keenan, 2013). I became interested in critical perspectives on psychology and, in particular, on psychosis (e.g. Pilgrim & Treacher, 1992; Johnstone, 2000; Bentall, 2003) and began writing in this area (e.g. Kinderman & Cooke, 2000; Cooke, 2008). As an academic, I am currently active in promoting professional and public debate about 'taken for granted' (Barrett, 1996) ideas in mental health (e.g. Cooke & McGowan, 2013; Cooke, Gilchrist, & McGowan, 2014; Cooke & Kinderman, in press). My current role at Canterbury Christ Church University, UK, includes teaching on a doctoral programme that trains clinical psychologists to work in the British National Health Service (NHS). This chapter describes some of the tensions inherent to teaching critical psychology in such a context. It also outlines the ways that colleagues and I have managed these tensions and developed teaching in this area such that the programme's critical 'edge' is now one of the aspects most valued by trainees (Chatfield, 2016).

In the UK, the profession of clinical psychology has evolved within the British NHS (Newnes, 2014; Hall, Pilgrim, & Turpin, 2015). Until the 1990s, many clinical psychologists were trained 'on the job' as part of 'in-service' training schemes run by the NHS (Lavender & Turpin, 2015). These in-service programmes gradually moved to higher education institutions. Currently all clinical psychology training is governed by universities and takes the form of a 3-year postgraduate professional doctorate.

As with other university-based professional training programmes – for example, nursing (e.g. Grant, 2014) – there is an inherent tension between the requirements of different stakeholders. On the one hand, the NHS requires workers to deliver the currently mandated interventions. For clinical psychology programmes, the pressure is to provide therapists trained and accredited to deliver standardised 'evidence based', 'empirically validated' or 'NICE compliant' therapies (NICE being the National Institute for Health and Care Excellence: see www.nice.org.uk) (Crits-Christoph, Frank, Chambless, Brody, & Karp, 1995; Court, Cooke, & Scrivener, 2016). Indeed, the standards for the accreditation of UK clinical psychology programmes have recently been revised to place more emphasis on this (British Psychological Society, 2014). This requirement to provide skilled-up workers is sometimes in conflict with an aim of higher education to teach critical, reflexive thinking and to encourage students to question orthodoxies and taken-for-granted ideas (Grant, 2014). This tension could perhaps be paraphrased as a conflict between the imperative to *train* and the imperative to *educate*. It also speaks to an ongoing debate about the nature and purpose of clinical psychology.

Theoretically, clinical psychologists have been valued for their knowledge of, and ability to appraise critically, a wide range of psychological ideas and theory. This wide knowledge and critical ability should make it possible to formulate unique problems at both an individual and a systemic level, in collaboration with those affected, thus enabling complex clinical decision-making. This was the conclusion of an influential review of the profession in the 1980s (Management Advisory Service to the NHS, 1989) and has been widely promulgated since (Gilbert, 2009; Pilgrim, Turpin, & Hall, 2015). Of course the review was commissioned by the Division of Clinical Psychology and was unlikely to conclude that clinical psychology was mainly an expensive version of counselling. There has, however, been a recent turn towards the privileging of standardised, protocol-based 'evidence based treatments' (Marks, 2015). Critics of this development have argued that by attempting to standardise clients (by means of allocation to diagnostic categories) and approaches to helping (protocol-based 'brand name' therapies), clinical psychology has sold its birthright (Hall & Marzillier, 2009). On a conceptual level, Pilgrim (2011) argues that this development marked a change from an 'idiographic' to a 'nomothetic' approach to human difference in a powerful and visible section of the profession:

> the uncritical acceptance of the ontological status of diagnostic categories drawn from psychiatry. The discourse . . . for psychologists not just psychiatrists became one of selectively treating particular reified disorders, such as "major depression", "anxiety disorders" "social anxiety disorders" "personality disorders" etc.
>
> *(Pilgrim, 2011, p. 122)*

In terms of application, some argue that clinical psychology may prove to have contributed to its own demise by reducing applied psychology to a set of techniques that managers can then arrange to be delivered by cheaper workers (Court et al., 2016). Diamond (2006, p. 6) argues that 'Clinical psychology is at risk of putting all its eggs in the basket of therapeutic techniques'.

This chapter takes the example of a teaching unit (module) in the third year of the Doctoral Programme in Clinical Psychology at Canterbury Christ Church University, UK. The module is compulsory for all students (known in this context as trainees) on the programme and takes place in their final year. By that point, trainees have had extensive experience of NHS services: practice placements (internships) run alongside lectures throughout the programme, so in the third year, trainees are on their fourth or fifth placement. The unit in question is entitled 'Psychology and Society'. It invites trainees to take a step back and reflect critically on the role played by psychology – both the academic discipline and the profession – in our society, together with the role played by mental health services more generally. The latest accreditation standards for clinical psychology programmes issued by the British Psychological Society state that graduates need to understand 'social approaches to intervention; for example, those informed by community, critical, and social constructionist perspectives' (Committee on Training in Clinical Psychology, 2014, p. 23). Accordingly, our programme's 'Psychology and Society' unit exposes trainees to various critiques and invites them to consider their own position relative to the different debates and to think about 'the type of psychologist they want to be'. While much of clinical psychology training could be seen as 'domesticating' (Wellington & Austin, 1996), in the sense that tutors are passing on accepted ways of going about things within the profession, this unit aims to be 'liberating' (Wellington & Austin, 1996) in that its aim is to enable trainees to engage with various critiques of clinical psychology as usually practised. I 'top and tail' the unit with an introduction and then a final half-day reflective session, but most teaching is delivered by visiting contributors. I see it as a priority to involve critical thinkers who have publicly articulated their ideas. Those involved change from year to year, but have included: Diana Rose, David Smail, Lucy Johnstone, Guy Holmes, Jennifer Clegg, Peter Kinderman, Odi Oquosa, David Pilgrim, Rufus May, Joanna Moncrieff, Bob Diamond, David Fryer, Jay Watts, Clare Crestani (Mad Hatters of Bath), Lucy Clarke (Special Yoga), Uma Dinsmore-Tuli and Nirlipta Tuli (Yoga Nidra Network), SAGE (Salomons Advisory Group of Experts, our programme's service survivor group), and Psychologists Against Austerity. The aim is to create the opportunity for genuine dialogue with original thinkers. Students value hearing the arguments direct 'from the horse's mouth' rather than mediated by me. Engaging in real dialogue also lends ecological validity (Bronfenbrenner, 1979) to the sessions. I brief contributors about the aims and objectives of the block and give them a copy of the questions that trainees discuss in the introductory session (see boxed material below). Having done this, I leave them with freedom to structure their session (a day or half a day) as they choose.

The unit was used as a case example of innovative practice by the Mental Health in Higher Education Project, an initiative of the Higher Education Academy, which aimed to improve teaching about mental health within universities (Higher Education Academy, n.d.; Cooke, 2004). It is complemented by other units on community psychology and 'service user and carer perspectives' which have sympathetic aims and often draw on some of the same theoretical ideas (McGowan, 2015; Lea, Holttum, Cooke, & Riley, 2016).

As expressed in the programme handbook (McGowan, 2015), the aim of the unit is for trainees to be able to practise in a manner mindful of the debate about the function of clinical psychology and other professions within society. Its objectives are:

- To have an awareness of sociological, political and cultural perspectives on clinical psychology and related institutions.
- To have a thorough understanding of the debate about the role of psychology in our society.
- To have a detailed knowledge of ethical dilemmas for the profession.
- To develop a conceptual framework to examine issues of power and social inequalities and their relevance to clinical psychology knowledge and practice.

(McGowan, 2015, p. 49)

The topics covered include:

- Anthropological and sociological perspectives on British clinical psychology.
- Historical influences on the development of the profession, and how they affect current values and practice.
- Political interests and social forces that shape psychological theory and research, and how they are presented.
- The relationship between psychology and social policy.
- Power, discrimination and disenfranchised groups/minorities.
- Abuse by social systems, institutions and organisations (including psychology).
- The psychologisation of society, and therapy as 'the opium of the people'.
- Clinical psychology and the media.
- Alternatives to traditional mental health/psychology services.
- The interface between the personal, the professional and the political.

(McGowan, 2015, p. 49)

The unit evolved from a previous one entitled 'Models of Psychopathology'. In 2003, I was asked to design it in response to a recognition that there was insufficient space on the programme for trainees to reflect on the place of psychology within society or to familiarise themselves with, and consider their responses to, critiques of clinical psychology and other mental health professions. The relevant critiques emanate both from within the discipline and profession (e.g. Pilgrim & Treacher, 1992: Newnes, 2014) and from elsewhere, notably from disciplines such as philosophy, anthropology, sociology and from the service user/survivor movement (e.g. Spandler, Anderson, & Sapey, 2015). My brief then was to contribute to making the programme more critical, and to invite trainees to be 'questioning' many of the issues also apply in other settings where clinical psychologists work, such as physical health or learning disabilities.

Meyer and Land (e.g. Meyer & Land, 2003; Land, Meyer, & Smith, 2008; Meyer, Land, & Baillie, 2010) have put forward the idea of 'threshold concepts': core concepts that once understood, transform perception of a given subject. There are several ideas discussed in the unit, which have the potential to be threshold concepts for trainee clinical psychologists. These include:

1. *The role of the social environment in distress and 'mental illness':* the suggestion that clinical psychology, as commonly practised, tends to focus disproportionately on intrapersonal factors in explaining distress ('psychocentrism') and to pay relatively less attention to the events and circumstances of people's lives (Midlands Psychology Group, 2012; Cooke, 2014).
2. *The potential for professions to do harm as well as good, despite good intentions* (e.g. Moloney, 2013; Kinderman, 2014).
3. *The contested nature of mental health and professional practice* (e.g. Kinderman, 2014; Loewenthal, 2015).
4. *The potential value of 'not knowing'* as opposed to having to be an 'expert' (Anderson & Goolishian, 1992).
5. *The often unseen and unacknowledged role of vested interests in maintaining the status quo* (Smail, 2005).

In approaching this unit, my aim was to expose trainees to critiques of clinical psychology as commonly practised. This creates space for them to engage with these critiques and to voice their own questions and doubts, and, it is hoped, come to some resolution about the kind of clinical psychologist they aspire to be. I took as a starting point those questions that my own experience of both training and clinical practice had thrown up. My philosophy of teaching (Pring, 2000) draws on the following (overlapping) principles and these are reflected in my approach to this unit.

- A critical realist approach to knowledge (Dragonas, Gergen, McNamee, & Tseliou, 2015). Critical realism is a 'halfway' position between realism (the idea that our perception is an accurate reflection of a knowable and measureable reality) and social constructionism (the idea that knowledge is constructed by discourse) (Fleetwood, 2013).
- The value of 'not knowing' (Anderson & Goolishian, 1992). Based on critical realism, this approach conceptualises the role of the therapist or educator as primarily one of facilitation rather than one of imparting 'expertise'.
- A humanistically informed adult learning model (Knowles, 1990). Humanistic approaches (e.g. Rogers, 1961; May, 1969) assume that (like plants) humans have an innate potential for growth and development, given the right conditions. The role of the therapist or educator is not so much to impart wisdom as to help create these conditions. The adult learning approach, also known as andragogy

(Knowles, 1990), values and tries to capitalise on the existing knowledge that adults bring to a learning situation. It is problem-based and collaborative rather than didactic, and emphasises more equality between teacher and learner, commitment to 'education' and specifically to the development of critical thinking, over 'training' in the sense of passing on accepted ways of going about things (Grant, 2014).

- Reflective practice (Schön, 1991, 2009). This approach suggests that practitioners learn and develop by continually reflecting on their actions and practices, and on the values and theories that inform them. It is a popular approach in clinical psychology (Lavender, 2003) and is an explicit tenet of our programme: we aim to train 'reflective practitioners' able to learn continuously in this way even after they qualify (Salomons Centre for Applied Psychology, 2015).
- A growth mindset (Dweck, 2000): talents and abilities are not fixed, but can be developed through effort, good teaching and persistence, including learning from failures.

I first generated a list of questions (see below), drawn from critiques of psychology, and then revised it on the basis of feedback from a range of people including academics, clinicians, service users and those who prefer to be called 'survivors'. I circulate the questions to the trainees at the beginning of the unit and host a session where they debate them in small groups. In the second, plenary part of the session, each group facilitates a debate in the wider group on their particular question.

DOCTORAL PROGRAMME IN CLINICAL PSYCHOLOGY (CCCU): THINKING ABOUT THE ROLE OF PSYCHOLOGY IN SOCIETY

Anne Cooke

Possible topics for group discussion

1. Epistemological, historical, political and cultural perspectives on clinical psychology and related institutions
    - What have the historical influences been on the development of the profession, and how do they affect current practice?
    - How might anthropologists view British clinical psychology?
    - Why are the majority of our clients women, while men are 'over-represented at the sharp end of psychiatry – admissions, detentions, secure and forensic services' (Rose, 2001, n.p.)?
    - Why are black people 'often denied the softer therapies of psychologists' (Rose, 2001, n.p.)?

- To quote Kutchins and Kerk (2003, p. 21):

> As you reflect on conversations you have had during recent weeks, you recall that your cousin, a young stockbroker, complained of not sleeping well; . . . a colleague at work, who is single, appears to always choose to be alone after work; a close friend confided that she has almost no sexual desire for her husband; your supervisor's 10-year-old is in trouble at school; . . . your partner has been feeling blue and your sister can't stop obsessing about a former boyfriend. In addition, you are really worrying about an upcoming speech. According to DSM-IV, each of the behaviours above is listed as a criterion for one or more mental disorders.).

Has our society's increasing tendency to medicalise the ups and downs of everyday life gone too far?

2. The debate about the role of psychology in our society

    - Oprah Winfrey syndrome: has society's psychologisation gone too far?
    - To what extent are we just 'modern day priests', hearing confession?
    - Is psychological therapy just 'the opium of the people'?
    - Are we part of the solution or part of the problem?
    - If we agree with Kenneth Gergen (1990) that concepts of 'healthy functioning' are suffused with moral and cultural assumptions, what might this mean for our practice?

3. The debate about whether efforts directed at changing individuals would be better directed at changing society

    - David Smail (1993, 1996) has argued for an environmentalist psychology in which therapy is a secondary part to socio-political change and ordinary relationships. He argues (1996) that rather than seeing people as 'manipulable deviants from unassailable norms', we should see them as 'characters in search of public structures which are generous enough to accommodate them, . . . honest enough to acknowledge their private pain and take account of the lesson it teaches'. To what extent do you agree with him?
    - Rachel Perkins (2000, n.p.) advocates de-emphasising therapy in favour of a rights-based approach:

> 'The wider disability movement did not reject medicalisation in favour of a nicer therapeutic approach. They rejected it in favour of rights – to employment, to be educated, to travel, to vote, to

> stand as a politician . . . But still the mental health world puts most of its energies into debating which treatments and services people should have – rather than the rights that could transform our lives so much more profoundly'.

What do you think?

- A press release by the UK Community Psychology Network (2007) about the IAPT initiative made the following statement:

> Cognitive Behaviour Therapy and associated approaches are comprehensively problematic . . . Moreover, these treatments individualise social problems, draw attention away from the more important social economic and material causes of distress and position individual cognitive dysfunction as both the cause of the person's problem and the locus for intervention. It is bad enough to be depressed because of difficult living circumstances or to be anxious because you are subjected to regular domestic violence, without being told your depression or anxiety are caused by your own dysfunctional cognitions. Blaming the victim like this imposes irrelevant therapeutic rituals on top of societal oppression.

To what extent do you agree?

4. The debate about ethical dilemmas for the profession

- How might we negotiate the interface between the personal, the professional and the political in our work?
- Harper (1999, n.p.) wrote:

> There is a need for therapists and professionals to be more honest about the essentially arbitrary and contingent nature of their language, concepts and even treatments . . . to be more openly pragmatic with users rather than pretending there is some secret expert knowledge,

If we don't make this claim, are our high salaries justified?

- Do you agree with Diana Rose (2001) that the usual discourse of the clinical psychology profession is 'self-congratulatory'? If so, why do you think this is?
- Clinical psychologists often work as part of wider systems (e.g. institutions) that are arguably damaging to clients. Is it best to work

for change from within or to leave and work elsewhere? If the former, how can we avoid becoming part of 'the problem'?

5. The politics of theory and research

    - Is theory used as a gloss on application which has been undertaken for quite different reasons (Potter, 1982)? Does it matter?
    - 'Researchers need to locate the interests that may have shaped their own research and need to refuse funding by drug companies' (Harper, 1999, n.p.). What might some of the interests and forces be that shape our research as clinical psychologists in the NHS?
    - Do you agree with David Pilgrim and Andy Treacher (1992) that clinical psychologists' practice is more influenced by discussions with colleagues and experience than by published research, and that many see research as nothing more than a rhetoric of professional legitimisation?
    - Mary Boyle (2000, n.p.) argues that

> research is always potentially influential. Whether we approve it, intend it or are even aware of it, our work will have influence in so far as particular psychological ideas become part of the construction of reality, which is then drawn on by policy makers to frame both social problems and their perceived solutions. . . . Forexample, the idea that we all have personalities and that these personalities can become disordered.

If we accept her argument, what might its implications be?

6. Debates about clinical psychology, social responsibility and service user critiques of clinical psychology

    - 'For damaging ideas to flourish requires only that those who know better remain silent' (based on Burke, 2016). We frequently see examples of unhelpful media coverage about mental health problems, and sometimes hear politicians making misinformed statements. Should clinical psychologists contribute to the public debate about our areas of expertise? In the media? In the political debate?
    - Carla Willig (1998, p. 96) argues that we

> find ourselves within a context in which things are always already going on or being done. Within this context it is impossible to abstain from involvement since inaction is always a form of action.

> Thus, we can only ever argue for or against, support or subvert particular practices or causes but we can never disengage ourselves from them.

If we accept her argument, what might its implications be?

- According to Harper (1999, n.p.):

> In this apparently post-modern world of ours the old overarching grand narratives have broken down and it is possible for the practitioner to either feel so paralysed by competing ideas that they cannot move forward, or feel the only way to do anything is to ignore many critical voices and instead simply engage with the individual client. The harder choice is to enter that ambiguous terrain where we act strategically to do what is possible in our individual positions whilst continuing to question dominant ideas and practices.

What might this mean in practice?

- How might the current limited dialogue between clinical psychology and those who use its services be developed? What changes might clinical psychologists be able to make to their thinking, practice and professional structures as a result?
- Foucault (1967, p. xii) observed that for centuries there has been a 'monologue of reason about unreason'. Similarly, Peter Campbell (2000) comments that while professionals are gradually accepting the idea that 'consumers' might be able to comment on the services that they use, there is greater reluctance to accept users and survivors as agents able to reflect on their mental distress and to provide valuable understandings of it. He notes (p. 201) that 'what many service providers seem to hanker after is raw evidence, uncontaminated by reflection'. Diana Rose (2001, n.p.) comments that 'power is at stake because dominant discourses and practices will always try to undermine us by pathologisation and exclusion'. How can we contribute to the evolution of the monologue into a dialogue with those traditionally positioned as 'unreason'?
- What aims might we have in common with those of the user/survivor movement? How might we be able to work together in pursuit of those aims?

Following sessions by the external speakers, I facilitate a final reflective session where trainees are invited to consider the following three questions:

1. Which ideas have most resonated with you in this unit?
2. What have you found most difficult/challenging?
3. How, if at all, has your thinking changed about the type of clinical psychologist you want to be?

Reflection on the unit

The unit appears successful: it is consistently highly evaluated by students, has survived a number of curriculum reorganisations since its inception in 2001, and I have managed to continue to persuade busy and high-profile people to come and teach on it! Importantly, given its inherent critical stance, it has consistently been supported by other members of the programme team. The programme is known for its invitational stance towards critical perspectives (British Psychological Society, 2016) and trainees often cite this as a reason for having applied to us in particular (Chatfield, 2016). Our educational philosophy is articulated in the *Programme Handbook* (Salomons Centre for Applied Psychology, 2015):

> A broad theoretical/knowledge and experience base underpins the Programme. The Programme is based on a growing body of psychological knowledge, which draws on a range of theories considered of relevance to the work of clinical psychologists including behavioural, cognitive, psychoanalytic, systemic, humanistic, social constructionist, community, critical and biological. The Programme aims to provide trainees with the experience, knowledge and skills necessary to conceptualise a problem from a number of different theoretical viewpoints and to use the practice associated with this range of models.
>
> Whilst psychology is the main knowledge base for practice, the importance of integrating contributions from other bodies of knowledge, including sociology, politics, organizational theory, ethics, philosophy, education, management, legal/judicial, informatics, economics and anthropology is also recognised. Training, therefore, aims to provide input from these bodies of knowledge when relevant to practice.
>
> The Programme . . . aims to integrate three models of clinical psychology practice . . . the scientist practitioner, the reflective practitioner and the critical practitioner . . . A critical approach places value on challenging the construction of knowledge and practice to promote emancipation and social justice and reduce the risk of harm.
>
> *(Salomons Centre for Applied Psychology, 2015, p. 10)*

Trainees' responses to the unit

I had been concerned that the students might feel oppressed by exposure to – sometimes quite damning – critiques of clinical psychology. I have not found that to be the case. Trainees value the contact with people who hold passionate opinions and who are prepared to speak openly about their views. They enjoy the opportunity to debate amongst themselves, on occasions continuing heated discussions over breaks. The inclusion of a final session devoted entirely to structured reflection, discussion and debate seems to be particularly appreciated. A typical piece of feedback was:

> The structure allowed us the space to think and express ideas that were in development in the previous teaching but were not discussed there. We greatly enjoyed the session and would really like to have a lot more of this . . . it was a really good experience having the opportunity . . . to get together and discuss the ideas raised in teaching the day before. This left people wanting more of this, so the year group is asking if a half day debate or seminar at the end of each teaching unit can be incorporated into the teaching schedules.

This approach to teaching provides opportunities for trainees to voice doubts and questions, which have arisen in their clinical placements, and to begin to theorise them and to think about how they personally want to practise. A 'learning cycle' (Kolb, 1984) is thus set up. They seem to appreciate my acknowledgement that many of the questions discussed in the unit are ones thrown up by my own experience of working as a clinical psychologist in the NHS. They benefit from the chance to synthesise ideas and consider the kind of practitioner they want to be. I have been struck by how new some of the ideas have been to some of them, even after 3 years with us. The teaching seems well placed in the third year of the programme, by which time trainees have been exposed to a number of placement settings on which to reflect.

Challenges

The first challenge has been the obvious one: the inherent tension between two of the aims of NHS-funded clinical psychology programmes. On the one hand, programmes need to provide workers able to deliver the 'evidence based practice' that NHS organisations are currently mandated to provide. On the other hand, the programmes also aim to educate creative, critical thinkers which I would argue the NHS urgently needs. The profession has to balance its different commitments to the NHS. The first is to meet immediate service demands, which in the present context are often for 'doers' rather than thinkers. For example, many current posts are linked to the provision of a particular 'brand name therapy'. This has to be balanced with a parallel commitment to thoughtful practice under the rubric of the profession's 'scientist practitioner', 'reflective practitioner' and 'critical practitioner' models. The traditional model informing NHS clinical psychology provision was one of generic mental health services employing professionals with a broad training, able to draw on theoretical first principles to provide individualised treatment based on a collaborative formulation. However, this is increasingly being replaced by one of therapy model-specific services employing therapists with a shorter training in one, NICE-approved, model only, and offering predetermined, short packages of care to people with a particular diagnosis (Cooke & Watts, 2016). Commentators have linked this development to the current dominance of 'naïve modernism' in the intellectual sphere (Bohart & House, 2008; Faris & van Ooijen, 2011), an anxiety-driven and vain quest for 'safe certainty' on the part of clinicians and managers (Mason, 1993; Court, Cooke, & Scrivener, 2016), and in the political sphere of market capitalism, 'austerity' measures and privatisation of public services (Cooke & Watts, 2016). My own programme is exposed to this pressure along with the others, and I have sometimes had to avoid some of my teaching time being diverted to other activities such as therapy skills training.

The second challenge in providing this teaching unit has been financial: the use of external contributors, many of whom are self-employed and come from far afield places some strain on the programme budget. On the basis of student feedback, I have been able to convince budget holders of the excellent value for money this input represents.

A third challenge has concerned the relative scarcity of related practice placements. I have found it fairly easy to find people to talk about conceptual critiques of clinical psychology, but increasingly hard to identify local practitioners able to base their practice wholly or mainly on such ideas. Recently we have begun to make links with third-sector organisations engaged in more critically-informed community practice (see, for example, Rhodes, 2016).

What makes it possible despite the challenges?

In thinking about what enables such a currently counter-cultural teaching unit to survive and thrive, three factors come particularly to mind.

The first is the consistently positive evaluation by students (not to mention the willingness of the speakers to travel long distances to do this teaching, for which I am eternally grateful!).

Second, in revising its accreditation standards for programmes (British Psychological Society, 2014), the British Psychological Society's Committee on Training in Clinical Psychology, while still responding to the current focus on 'model-specific' therapy skills, has managed to withstand the pressure to squeeze out the more critical elements. The way this tension is managed in the current guidelines reflects the rich debate about the 'evidence based practice' approach within the profession (see, for example, Pilgrim et al., 2015; Court et al., 2016)

Third, the support for critical approaches within the university (e.g. Lavender, 2003), school (Burns, 2014), programme leadership and team (see above), has been enormously helpful. I can certainly think of other universities and departments where a unit like this might be much harder to introduce and sustain.

Does it make any difference?

Trainees really appreciate not only this particular teaching, but also the exposure to critical ideas in the wider programme. Comments about the programme in *The Alternative Handbook for Postgraduate Training Courses in Clinical Psychology* (British Psychological Society, 2016, n.p.) include, in response to the question: 'What would you say is your favourite aspect of your course?'

> - The course teaches you to be very critical in your thinking and encourages you to develop your own opinions and viewpoints.
> - I like the emphasis on critical psychology and social constructivism.
> - Its critical and reflective stance on mental health.
> - I particularly like the critical focus of the course and the emphasis on lived experience.
> - The exposure to a wide range of content. It really does challenge your ways of thinking (irrespective of your positioning) allowing for awareness of alternative views.
> - It is the type of course that builds you into an extremely competent practitioner while allowing you to maintain your sense of self.
> - Very reflective; this can be the most challenging and best part of it. Don't think you can just take training super casually on the chin.
> - The focus on values, which the course has above any particular therapeutic model.
>
> *(British Psychological Society, 2016, n.p.)*

And my particular favourite: 'If you like the idea of spending a lot of time thinking about complex questions which might not have any answers, this is the course for you.' (British Psychological Society, 2016, n.p.)

Feedback from clinical placement supervisors (some of whom take trainees from a number of courses) is also generally that they value Salomons' trainees' critical thinking, values-based practice and willingness to engage in debates and tolerate uncertainty. It is harder to judge the extent to which engaging in these discussions during training actually makes a difference to the way trainees subsequently practise post-qualification. Some have gone on to found their own third-sector organisations (e.g. MAC-UK; www.mac-uk.org) or to be active in social movements such as Psychologists Against Austerity (https://psychagainstausterity.wordpress.com). Most, though, are in NHS jobs where the opportunities to put this critical thinking into practice vary widely. Many provide placements to current trainees, so programme staff have an opportunity to visit them. Often what we hear is that they are able to find some ways to practise in accordance with their beliefs and values, partly shaped by the thinking they encountered on the programme, even when these are at odds with the current culture of the NHS. A recent research project provides some evidence of this. Court et al. (2016) interviewed local clinical psychologists, many of whom will have trained on our programme. We found that as a result of the pressure to be 'NICE-compliant' (Murphy, 2013), clinical psychologists sometimes claim to be doing protocol-driven, single-model therapy while actually conducting much more sophisticated interventions. These draw on a range of psychological theory, including critical ideas, and are based on an individualised formulation co-constructed with the service user. I like to think that hidden in local NHS services, among the uniform plantations of 'NICE- compliant therapy providers', there lurk some 'guerrilla thinkers' doing thoughtful, democratic, client-centred work and being comfortable with 'not-knowing' (Anderson & Goolishian, 1992).

Despite the challenges and the questions, organising this unit remains one of the most satisfying elements of my role: a chance to engage trainees in debates that I think are vital not only to the profession, but more importantly, to those whom we are aiming to help.

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Responses to the Publication of the American Psychiatric Association's *DSM-5*

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Abstract

The idea and practice of diagnosis in psychiatry has always been controversial. Controversy came to a head in the period preceding and immediately after publication of the latest version of the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders–Fifth edition*. There was widespread international discussion and debate not only in scholarly journals but in mainstream and social media, and to the formation of International DSM Response Committee and an International Summit on Psychiatric Diagnosis. This article documents that process and outlines the issues that provoked, and continue to provoke most controversy, from the (admittedly personal) perspective of those involved. It ends with suggestions of alternatives to diagnosis, which avoid some of these problems and outlines how these are being taken forward. The next 10 years are likely to see significant change.

Keywords

DSM-5, history, criticism, opposition, response

Psychiatric Diagnosis in Social and Political Context

Psychiatric diagnosis has always been a contentious issue, but the storm of controversy that attended the development and release of the most recent

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version of the American Psychiatric Association's (APA's) *Diagnostic and Statistical Manual of Mental Disorders–Fifth edition* (*DSM-5* [APA, 2013]) was without precedent. This article describes the history of opposition to these reforms between 2011 and 2015. The latest revision of the *DSM* franchise will be placed in a historical context, including the influence of social and political factors on the various editions over time. However, this article will particularly focus on the activities undertaken by members of the British Psychological Society (BPS) and Division 32 (the Society for Humanistic Psychology) of the American Psychological Association. As such, it must be seen as a personal and narrative account rather than an independent and neutral historical analysis.

Psychiatric diagnosis has always been controversial, and has never remained the same for long. A rather remarkable editorial in *The London Times* (Anonymous, 1854) of Saturday July 22nd 1854, commenting on the question of madness in a notorious criminal case, stated that:

> Nothing can be more slightly defined than the line of demarcation between sanity and insanity. Physicians and lawyers have vexed themselves with attempts at definitions in a case where definition is impossible. There has never yet been given to the world anything in the shape of a formula upon this subject which may not be torn to shreds in five minutes by any ordinary logician. Make the definition too narrow, it becomes meaningless; make it too wide, the whole human race are involved in the drag-net. In strictness, we are all mad as often as we give way to passion, to prejudice, to vice to vanity; but if all the passionate, prejudiced, vicious, and vain people in this world are to be locked up as lunatics, who is to keep the keys to the asylum? (p. 2)

Psychiatric diagnostic criteria are revised regularly. It is often assumed that these changes are driven by scientific advances—an enlightened movement from falsehood to objective clarity. But it makes more sense to see our classificatory systems in mental health as historical technological documents whose development has been driven by the current social, political, economic, and other contextual forces (Foucault, 1967). Despite our hope (or contention) that the frequent updates of diagnostic manuals reflect scientific progress (Kendler, 2014), we might better regard such changes as indicative of the sociopolitical needs and values of the time (Bowker & Star, 1999; Fulford, Thornton, & Graham, 2006; Scott, 1990). The 1854 example quoted above is remarkable in the degree to which it reflects the 21st-century concerns about the role of psychiatric diagnosis addressed later in this article. These questions arose in 1854 in the context of a horrific murder, which challenged contemporary beliefs about the nature of mental health and illness. The "the line of demarcation between sanity and insanity" (Anonymous, 1854, p. 2) has been constantly questioned since 1854. Social forces ebb and flow, and our approaches to psychiatric diagnosis change with them.

In that context, it seems appropriate to set out some of the chronology and political history of, debate about, and opposition to the most recent reforms of the APA's *DSM*, namely the development of *DSM-5* between 2011 and 2015.

1956 to 1994: DSM-I to DSM-IV

The first edition of the *Diagnostic and Statistical Manual for Mental Disorders* (*DSM-I* [APA, 1952] and the second edition *DSM-II* [APA, 1968]) are widely held to reflect the political and social needs facing the U.S. Veterans Administration at the end of the Second World War (e.g., Pilgrim, 2014). There was a clear need to identify and respond to the mental health problems of large numbers of returning servicemen (many of whom had been traumatized by war and in any event required an efficient service). The problems experienced by veterans were a clear demonstration of the role of social and environmental factors in mental health. This, together with the psychodynamic and psychoanalytic approaches popular at that time (APA, 2015), led to pressure to conceptualize mental health problems in a more inclusive manner than merely to isolate the "insane" in asylums (Grob, 1991). Subsequent revisions, namely *DSM-III* (APA, 1980) and DSM-IV (APA, 1994) have been argued to reflect something of a crisis of legitimacy for psychiatry, with the significant changes introduced in *DSM-III* seen as a desire to align mental disorders more closely with physical illnesses (Mayes & Horwitz, 2005). Many have commented that just as *DSM-I* reflected the social needs of the Veterans Administration at the end of Second World War, these changes may reflect the political and financial needs of professional bodies, as well as health insurance and pharmaceutical companies (Mayes & Horwitz, 2005; Pilgrim, 2014; Tsou, 2011).

With regard to specific diagnoses, it is noticeable that over the history of the *DSM*, some diagnoses have been removed (hysteria, homosexuality), and some experiences (gender dysphoria, hearing voices) have changed from being seen as inherently pathognomic toward being seen as pathological only if the individual finds them distressing. Equally, some diagnoses appear to have been created primarily for political purposes, for example, posttraumatic stress disorder (PTSD) emerging in response to the identified distress of military veterans (and which will be discussed briefly below) and "dangerous and severe personality disorder" emerging in response to the apparent needs of the criminal justice system when confronted by people who are repeatedly violent (Pickersgill, 2013). The latter is a peculiarly U.K. phenomenon and not present in DSM-IV or *DSM-5*, but is illustrative of the point. These changes appear to have had more to do with social and cultural movements than with scientific progress. For example, although the reasons for the removal of hysteria as a diagnosis are complex, a significant contributing factor appears to have been the rise and development of women's rights and changing gender roles in the 20th century (Ussher, 2013). Similarly, the initial inclusion of homosexuality as a diagnostic category (in the first edition of the *DSM* in 1952), its subsequent removal in 1973, and the later removal of "ego-dystonic" homosexuality from the *DSM-III-R* in 1986, all appear to reflect political and social changes: the first legislation to decriminalize homosexuality was passed in the United States in 1962 and in England and Wales in 1967 in response to the rise of gay rights campaigns (Kutchins & Kirk, 1997; Pilgrim, 2014). Recently, the World Health Organization has called for the removal of all disease categories in the forthcoming *ICD*-11 (11th Revision of the International Classification of Diseases) that relate to sexual orientation (Cochran et al., 2014). Again reflecting civil rights movements, similar changes can be seen in diagnostic criteria for so-called "personality disorder" (itself a contested term) in response to changing cultural norms about "obscene language" and "monogamous relationships" (Wakefield, 1996), as well as complex changes to the definitions and nomenclature of "paraphilias" (Wakefield, 2013).

As some diagnoses disappear, others emerge. PTSD was first introduced in *DSM-III* (APA, 1980) and has been seen as a response to the aftermath of the Vietnam War. By receiving a PTSD diagnosis, traumatized veterans could access medical or psychological care while avoiding both the stigma of other psychiatric diagnoses on the one hand, and criticisms of malingering or cowardice on the other (Galatzer-Levy & Bryant, 2013; Helzer, Robins, & McEvoy, 1987; Scott, 1990). In the United Kingdom, perhaps one of the more interesting introductions (although not, admittedly, into the *DSM*) was that of "dangerous and severe personality disorder." This was initially merely an "administrative category" rather than a clinical diagnostic category, created by officials in the criminal justice system in the United Kingdom in 2001 as a response to public anxiety around high-profile cases of assault and homicide. It acted as a focus for the provision of treatment with the aim of reducing reoffending (Burns et al., 2011; Ministry of Justice, 2011). The impetus for introducing such a category was overtly political, namely a wish to combine public protection, punishment, and treatment in a context of public fear and risk aversion (Manning, 2002). Although administrative in that it was never introduced into any clinical diagnostic manuals, it is clear that the label was taken up both from research and lay perspectives as if it were a diagnosis. For example, journal articles referred to "the treatment of individuals with dangerous and severe personality disorder" (Völlm & Konappa, 2012, p. 165) and in a House of Commons "Written Answer" "To ask the Secretary of State for Justice how many (a) adult and (b) juvenile prisoners have been diagnosed with dangerous and severe personality disorder" (Parliamentary Written Answers, 2008, Column 906W).

In that context, it is important to bear in mind that psychiatric diagnoses are shaped by, and in turn shape, our understanding of social norms, diversity, and difference—what it means to be deviant (Pickersgill, 2013; Pilgrim, 2014). Such classificatory systems also speak to how we understand (perhaps, even, how we allow ourselves to recognize) the psychological impact of adversity and social deprivation. As such, comments on psychiatric diagnoses are often social and political statements.

1999 to 2011: Revision of DSM-IV *to* DSM-5

To recap, there have been five revisions of the *DSM* since it was first released in 1952, with the second most recent major revision, DSM-IV, published in 1994. The 19-year period between the introduction of *DSM-IV* in 1994 and the final publication of *DSM-5* in 2013 was, therefore, relatively long. The planning process for *DSM-5* began within the APA in 1999 (see APA, 2014 for an official "timeline") with the publication of a number of "white papers" detailing proposed reforms, and discussion at professional conferences. The initial proposed revisions went out to APA members and all other interested parties in a public consultation in 2011. At the same time, so-called "field trials" of proposed new diagnostic criteria were started in a number of health care and academic settings (Clarke et al., 2013; Narrow et al., 2013; Regier et al., 2013). These were to run through to 2012 (APA, 2014).

2011: Public Consultation on the DSM Reform Proposals in 2011 and the British Psychological Society's Response

In the spring of 2011, the APA posted their draft (revised) diagnostic criteria on a public website and opened a 2-month period of public consultation. The BPS took the opportunity to respond in June 2011 (BPS, 2011). The BPS (2011) response was prepared by the current first author (PK), with contributions from Susan van Scoyoc, David Harper, David Pilgrim, Richard Bentall, Lucy Johnstone, Amanda Williams, and Pamela James, and subsequently consulted on widely among members, before being considered, edited, and approved by relevant boards of the BPS. In addition to specific comments, it included the general statement that:

> The Society is concerned that clients and the general public are negatively affected by the continued and continuous medicalisation of their natural and normal responses to their experiences; responses which undoubtedly have distressing consequences which demand helping responses, but which do not reflect illnesses so much as normal individual variation. (p. 2)

This general—although powerful—expression of concern was elaborated in detailed responses to the proposals as apparent at the time of writing, and in more general statements regarding the theoretical framework employed. For example, the BPS (2011) commented:

> The putative diagnoses presented in DSM-V [*sic*] are clearly based largely on social norms, with "symptoms" that all rely on subjective judgements, with little confirmatory physical "signs" or evidence of biological causation. The criteria are not value-free, but rather reflect current normative social expectations. Many researchers have pointed out that psychiatric diagnoses are plagued by problems of reliability, validity, prognostic value, and co-morbidity. Diagnostic categories do not predict response to medication or other interventions whereas more specific formulations or symptom clusters might (Moncrieff, 2007). . . . Diagnostic systems such as these therefore fall short of the criteria for legitimate medical diagnoses. . . . We are also concerned that systems such as this are based on identifying problems as located within individuals. This misses the relational context of problems and the undeniable social causation of many such problems. For psychologists, our wellbeing and mental health stem from our frameworks of understanding of the world, frameworks which are themselves the product of the experiences and learning through our lives. (p. 2)

The BPS (2011) response continued:

> The Society recommends a revision of the way mental distress is thought about, starting with recognition of the overwhelming evidence that it is on a spectrum with "normal" experience, and that psychosocial factors such as poverty, unemployment and trauma are the most strongly-evidenced causal factors. Rather than applying preordained diagnostic categories to clinical populations, we believe that any classification system should begin from the bottom up—starting with specific experiences, problems or "symptoms" or "complaints." Statistical analyses of problems from community samples show that they do not map onto past or current categories (Mirowsky, 1990; Mirowsky & Ross, 2003). We would like to see the base unit of measurement as specific problems (e.g., hearing voices, feelings of anxiety etc.). These would be more helpful too in terms of epidemiology. While some people find a name or a diagnostic label helpful, our contention is that this helpfulness results from a knowledge that their problems are recognised (in both senses of the

> word) understood, validated, explained (and explicable) and have some relief. Clients often, unfortunately, find that diagnosis offers only a spurious promise of such benefits. Since—for example—two people with a diagnosis of "schizophrenia" or "personality disorder" may possess no two symptoms in common, it is difficult to see what communicative benefit is served by using these diagnoses. We believe that a description of a person's real problems would suffice. Moncrieff and others have shown that diagnostic labels are less useful than a description of a person's problems for predicting treatment response, so again diagnoses seem positively unhelpful compared to the alternatives. There is ample evidence from psychological therapies that case formulations (whether from a single theoretical perspective or more integrative) are entirely possible to communicate to staff or clients. We therefore believe that alternatives to diagnostic frameworks exist, should be preferred, and should be developed with as much investment of resource and effort as has been expended on revising DSM-IV. The Society would be happy to help in such an exercise. (p. 3)

Furthermore, more detailed critique in the BPS (2011) statement suggested that "classifying these problems as 'illnesses' misses the relational context of problems and the undeniable social causation of many such problems" (p. 2) and stated that the Society was "very concerned at the increasing use of this diagnosis and of the increasing use of medication for children, and would be very concerned to see these increase further" (p. 4). As illustrative examples, the BPS (2011) also raised particular concerns about diagnoses such as "Chronic Depressive Disorder (Dysthymia)," arguing that:

> . . . sadness and unhappiness . . . are deserving of help and intervention [but] are not best considered illnesses. We also note that, by regarding them as such, there is a danger of misunderstanding their nature and cause and applying inappropriate medical remedies. We have particular concerns at the inclusion of this diagnosis, whose essential characteristics: " . . . depressed mood for most of the day . . . " certainly reflects a state of affairs that any humane individual should attempt to address, but does not appear to reflect any form of medical illness. (p. 14)

In responding to the putative diagnosis of "Disruptive, Impulse Control and Conduct Disorders," the BPS (2011) commented that:

> Of particular concern are the subjective and socially normative aspects of conformist behaviour. We are very concerned that "headstrong" behaviour is considered to be pathognomic of an illness (in Oppositional Defiant Disorder). Many people—many governments—would like children and citizens to be less defiant and more compliant. However, it is not a symptom of illness to be

> defiant. It may be a social or psychological problem to be addressed, but it may, in some circumstances, be a characteristic to be praised. (p. 22)

Other concerns addressed "Substance Use and Addictive Disorders" where the Society commented that:

> We note with concern the concept of "Gambling Disorder." Gambling is a problem, and it is a social phenomenon and issue that requires study and response. However, we feel it is conceptually wrong to regard this as an illness with symptoms. (p. 23)

Of particular concern to the BPS (2011) was the proposed diagnosis of "Paraphilic Coercive Disorder," where the Society commented that:

> Rape is a crime, not a disorder. Such behaviours can, of course, be understood, but we disagree that such a pattern of behaviour could be considered a disorder, and we would have grave concerns that such views may offer a spurious and unscientific defence to a rapist in a criminal trial. (p. 25)

2011: American Psychological Association Division 32 (Society for Humanistic Psychology) "Open Letter"

In October 2011, Division 32 of the American Psychological Association published an "Open Letter" (http://www.ipetitions.com/petition/dsm5/), citing the BPS's statement and launching a petition expressing concerns about the *DSM-5* proposals. This Open Letter was initially inspired by and quoted sections of the BPS response detailed above and published only a few months earlier. It argued that psychologists, as " . . . consumers and utilizers of the manual, but . . . also producers of seminal research . . . " should be included in the development of *DSM-5* " . . . as a professional community" (Section 1).

As the BPS had done, the APA Division 32 also expressed concerns about " . . . the lowering of diagnostic thresholds for multiple disorder categories, about the introduction of disorders that may lead to inappropriate medical treatment of vulnerable populations, and about specific proposals that appear to lack empirical grounding" (Section 2; "Overview"). It drew attention to proposed changes that threatened to " . . . deemphasize sociocultural variation while placing more emphasis on biological theory" (Section 2; "Overview"). The authors continued:

> In light of the growing empirical evidence that neurobiology does not fully account for the emergence of mental distress, as well as new longitudinal

> studies revealing long-term hazards of standard neurobiological (psychotropic) treatment, we believe that these changes pose substantial risks to patients/clients, practitioners, and the mental health professions in general. (Section 2; "Overview")

In particular, the Open Letter suggested that there were risks to vulnerable people, especially children, adolescents and the elderly, and people with political, religious, or sexual behaviors not shared with majority cultures. It therefore proposed that there was a need for " . . . a descriptive and empirical approach that is unencumbered by previous deductive and theoretical models" (Section 2; "Overview").

Shortly after the publication of the Open Letter, officials of Division 32 (David Elkins, Brent Dean Robbins, and Sarah Kamens) wrote to a number of international colleagues in a range of professions, proposing a "coalition" to address the *DSM-5* concerns. Indeed, many of the most trenchant critics of *DSM-5* did not come from psychology organizations but were, rather, psychiatrists acting collaboratively with service users and charities (see, e.g., signatories to the petition at http://www.ipetitions.com/petition/dsm5/).

2011 to 2013: DSM-5 Response Committee and Related Activity

In the months from the autumn of 2011 to the early weeks of 2013, a variety of individuals and groups expressed concerns about—and support for—the *DSM-5* proposals. One notable critic was psychiatrist Allen Frances, who had served as Chair of the committee that had drawn up DSM-IV. There are many aspects to Frances' response to the *DSM-5* proposals. Many of his comments (see, e.g., Frances, 2011) reflect those of the BPS and American Psychological Association Division 32, as well as those of other prominent psychiatric critics (see, e.g., Double, 2013; Kinderman, Read, Moncrieff, & Bentall, 2013; Thomas, 2013; Timimi, 2012). For example, Frances (2011) called the petition: "an extremely detailed, thoughtful, and well written statement that deserves your attention and support" (introductory paragraph). He went on to say that it:

> . . . summarizes the grave dangers of DSM-5 that for some time have seemed patently apparent to everyone except those who are actually working on DSM-5. The short list of the most compelling problems includes: reckless expansion of the diagnostic system (through the inclusion of untested new diagnoses and reduced thresholds for old ones); the lack of scientific rigor and independent review; and dimensional proposals that are too impossibly complex ever to be used by clinicians. (Paragraph 2)

Frances' involvement in and support for such a campaign was undeniably significant. The fact that Frances was a major U.S. psychiatrist was particularly important since the campaign related to a project being undertaken by the American psychiatric establishment. He was also well-known as the Chair of the DSM-IV Task Force, and as such could be seen to have distinctive specialist knowledge. As an individual, Allen Frances also had great energy and enthusiasm, together with good media skills. In the months before and after the publication of *DSM-5*, Frances gave a large number of media interviews and his involvement was undoubtedly a major factor in the development of a high level of awareness in journalistic circles.

Aspects of Allen Frances' critiques of the proposed revisions were, however, disputed by some. Some suggested that he was motivated by the threat to DSM-IV royalty income (Greenberg, 2010), especially when France advocated a petition to boycott *DSM-5*, a move which would have left most U.S.-dominated health care institutions reliant on DSM-IV. Less personally, Frances' line sat somewhat uneasily with the majority of the leading figures in the emergent campaign groups, who tended to hold the view (first expressed by the BPS) that this issue was not so much whether *DSM-5* was a technically better manual than DSM-IV but the more fundamental issue of whether the whole idea of "diagnosis" and the language of "disorder" are very meaningful or useful in mental health, or unhelpfully medicalize what are largely psychosocial problems. These critics, from the BPS and APA Division 32 and elsewhere, tended to think that, while the proposed revisions to *DSM-5* were a retrograde step, DSM-IV had been little better in this regard. Despite this, Frances' involvement in and support of the campaign was a major asset.

As the campaign developed, led primarily by officeholders in the BPS and APA Division 32, it drew international support. Although many professional psychological organizations decided that it would not be appropriate for them to campaign on this issue, opposition to the proposed changes to *DSM* was widespread in Europe, especially in France, where the leadership of the psychiatrist and psychoanalyst Patrick Landman was key (see, e.g., COLLECTIF39, 2015).

By the beginning of 2013, with the publication of *DSM-5* scheduled for May of that year, the campaign had developed to become the "International DSM-5 Response Committee." A petition of support associated with the APA Division 32's "Open Letter" of October 2012 had, by February 2013, attracted the support of more than 50 mental health organizations and over 14,000 individual signatures. Representatives of a number of international psychological and mental health organizations were contacted by Brent Dean Robbins and Peter Kinderman to gather support for a "Statement of Concern" regarding *DSM-5*. The decision to ask for support for the statement was essentially pragmatic and consensual. Some colleagues, such as Jack Carney and Patrick Landman (see http://boycott5committee.com/), but also (presumably for different reasons) Allen Frances, advocated a boycott of *DSM-5*. Others took a more pragmatic view, arguing that such a call was unlikely to prove effective because of the entrenched position of diagnostic manuals such as *DSM* in the health care economy, and instead suggesting that (in the words of the organizers): "it is vitally important to alert our colleagues, the mass media, and consumers about some serious reservations with the current draft of the *DSM-5*" (introductory paragraph). In its entirety the "Statement of Concern" (International DSM-5 Response Committee, 2013) ran as follows:

> We believe that there is now overwhelming evidence that *DSM-5*:
>
> - Is the result of a secretive, closed, and rushed process that put publishing profits ahead of public welfare;
> - Is in many places scientifically unsound and statistically unreliable, and did not received a much needed and widely requested external scientific review;
> - Is clinically risky because of many new and untested diagnoses and lowered diagnostic thresholds;
> - Will result in the mislabeling of mental illness in people who will do better without a psychiatric diagnosis;
> - Will result in unnecessary and potentially harmful treatment with psychiatric medication;
> - Will divert precious mental health resources away from those who most need them.
>
> For these reasons, we have serious concerns about the new *DSM-5* scheduled for publication by the APA on 20th May, 2013.
>
> These concerns should be resolved through concerted, interprofessional, international dialogue. Such dialogue should involve detailed critique of these proposals, consideration of possible alternatives, including non-medical approaches such as the problem-focused approach and individual case formulation used in evidence-based psychological therapies. There should be comprehensive, peer-reviewed, scientific field testing of any proposed suggestions.

> Until these issues have been addressed, we believe that clinicians should not use DSM-5 in their clinical decisions and communications wherever possible. Wherever possible, researchers should choose not to use the scientifically unsound DSM-5 categories as the basis of their studies, especially as such invalid diagnoses may compromise their own findings. We believe that, due to the availability of safe and legal alternatives, healthcare planners, managers, and commissioners have no need to use DSM-5 for planning or billing purposes. Colleagues in the pharmaceutical industry should avoid the use of DSM-5 diagnostic codes in planning, conducting or reporting their work, especially as they bear little relationship to underlying biological mechanisms. In addition, journal editors should consider whether it is appropriate to publish scientific papers that unquestionably assume the reliability and validity of DSM-5 diagnostic categories. Finally, the media should be aware of the scientific, theoretical, and ethical problems in DSM-5 when reporting on mental health issues.

While the DSM-5 Response Committee therefore stopped short of calling for a boycott of *DSM-5*, its clear aim was to alert media organizations, prior to and on publication of *DSM-5*, that the issue of psychiatric diagnosis, especially as characterized in that proposed revision, was a very contentious one.

May 18th 2013: Publication of DSM-5 *Together With Academic and Media Commentary*

The *DSM-5* was approved by the APA Board of Trustees on December 1st, 2012 and published on May 18th, 2013. It is perhaps merely a reflection of global politics and the dominance of the English language, but the APA's *DSM* manual has become routinely referred to as a "bible" of psychiatry (e.g., *The Corbett Report*, December 11, 2013), and consequently the publication of a new edition attracted considerable international academic and media attention. It is not possible to list all academic and media commentaries here, but a few selected examples may be illustrative.

Kinderman et al. (2013) called for mental health workers and academics to "drop the language of disorder," arguing that clinicians and researchers are "likely to be more effective if they respond to an individual's particular difficulties rather than their diagnostic label" (p. 3). That this position reflects that of the International DSM-5 Response Committee is perhaps unsurprising given that some of these authors were committee members. More independently, both *The Lancet* and the *British Medical Journal* (U.K. based, but nevertheless very influential medical publications) published editorials expressing significant concerns about *DSM-5*. An editorial in *The Lancet* (The Lancet, 2012), published before the publication of the revised manual

Figure 1. *British Medical Journal* cover for 25th May, 2013.

focused on the proposed removal of an exclusion period before a diagnosis of "major depressive episode" could be made in someone recently bereaved. The editorial commented that: "Grief is not an illness; it is more usefully thought of as part of being human and a normal response to death of a loved one" (p. 589), and "medicalising grief, so that treatment is legitimized routinely with antidepressants, for example, is not only dangerously simplistic, but also flawed" (p. 589). *The Lancet* did not expand on this analysis and did not issue another editorial comment after the publication of *DSM-5*, but it seems clear that its analysis—at least with respect to the issue of grief—is consistent with that of the *DSM-5* critics.

The *British Medical Journal*, focused on the publication of *DSM-5* in its edition of May 2013, with the cover page title of "Too Many Labels?—the controversy over *DSM-5*" (see Figure 1) and a feature article entitled "*DSM-5*: a fatal diagnosis?" (Gornall, 2013). Although these articles covered much of the same material discussed above, it is significant that the *British Medical Journal* chose to use the word "controversy" and to frame its editorial in terms of the need for debate.

In an interesting sideline to these discussions, the (now former) Director of the U.S. National Institute of Mental Health (NIMH), Thomas R. Insel, published a blog on April 29th, 2013 (Insel, 2013) which was widely interpreted as being highly critical of *DSM-5*. In it, Insel wrote that "The weakness [of *DSM-5*] is its lack of validity" . . . "Patients with mental disorders deserve better." He went further, suggesting that NIMH (a major and very influential funder of psychiatric and psychological research) would no longer use *DSM-5* as the basis of its research, stating "it is critical to realize that we cannot succeed if we use *DSM* categories as the 'gold standard.'" Instead, Insel suggested, NIMH would eventually use its own, different system, the Research Domain Criteria, which is currently in development (NIMH, 2011). Insel's intervention, perhaps in the context of an audience already alert to "controversy," fueled the debate and the resulting headlines included "Goodbye to the DSM-V" (McKay, 2013), "Federal institute for mental health abandons controversial 'bible' of psychiatry" (Drummond, 2013), "National Institute of Mental Health abandoning the *DSM*" (Bell, 2013), "Psychiatry divided as mental health 'bible' denounced" in the widely read *New Scientist* (Coghlan & Reardon, 2013) and—in the highly respected *New York Times*—"Psychiatry's guide is out of touch with science, experts say" (Belluck & Carey, 2013).

In a move which some found surprising and suspected was a reaction to the press coverage (e.g., Hickey, 2013), Insel subsequently issued a joint statement on behalf of NIMH with Jeffrey Lieberman, president of the APA (Insel & Lieberman, 2013). In that statement—which appeared to many to be something of a volte-face for NIMH—the two authors stated that *DSM-5*: " . . . represents the best information currently available for clinical diagnosis of mental disorders. Patients, families, and insurers can be confident that effective treatments are available and that the *DSM* is the key resource for delivering the best available care . . . . " The NIMH has not changed its position on *DSM-5*.

The Controversy Finds Its Way Into Popular Culture

Raising awareness of the controversy over the diagnosis of psychiatric "disorders" was a key aim of the self-styled "International DSM-5 Response Committee" and a significant clause in its "Statement of Concern" (International DSM-5 Response Committee, 2013). This aim appears to have been achieved: the idea that the development was controversial and found its way into popular culture. In addition to the *New York Times* piece (Belluck & Carey, 2013), perhaps the most striking example was its mention in the hugely popular animated series *The Simpsons*. In Episode 12 of Season 25,

Figure 2. Screenshot of Simpsons Episode 12, Season 25, "Diggs."

protagonist Bart Simpson meets a boy named Diggs (voiced by Daniel Radcliffe), whose eccentricities attract Bart but also require explanation. In conversation with Bart, Diggs comments: "The rumors of my bonkertude have been greatly exaggerated. *DSM-5* indicates paranoid schizophrenia, but that work is mired in controversy. Mired" (see Figure 2).

The Present

The campaign fought over the first few months of 2013 appears to have had a lasting impact. There is now an ongoing and vigorous debate over the reliability, validity, utility, epistemological status, and humanity of psychiatric diagnosis in general and of *DSM-5* in particular. There now appears to be widespread realization that the issue of psychiatric diagnosis is indeed contentious. One example was perhaps the debate about the status and meaning of "depression" that followed the death by suicide in 2014 of the actor Robin Williams (e.g., Cooke, Gilchrist, & McGowan, 2014).

Another indication of the extent to which the debate has challenged the status quo has perhaps been the reaction to the publication by the BPS of its report *Understanding Psychosis and Schizophrenia* (Cooke, 2014; see our second article Special Issue #2). Although unrelated to the publication of *DSM-5* in that the document was a scheduled replacement for a previous one (British Psychological Society, 2000), the report's message was highly relevant: "Professionals should not insist that people accept any one particular framework of understanding, for example the idea that their experiences are symptoms of an illness" (p. 6). Indeed, when *The New York Times* published a favorable piece on the report (Luhrmann, 2015), former President of the APA Jeffrey Lieberman (mentioned above) was motivated to post a personal video blog. The blog was entitled "What Does the *New York Times* Have Against Psychiatry?" and showed him wearing a scientist's white coat (Lieberman, 2015). In it, he criticized not only the New York Times article but also the original BPS report, suggesting that the material could have the effect of: "challenging the veracity of diagnoses and giving people who have symptoms of a mental disorder, license to doubt that they may have an illness and need treatment." In light of the above quote from the report, it may be that Lieberman has correctly interpreted this aspect of its message, but disagrees with it. Lieberman's blog itself provoked widespread comment ranging from agreement (e.g., Pierre, 2015) to interpretation as evidence of a "crisis of legitimacy" for psychiatry (e.g., Cornwall, 2015).

The widespread media coverage indicates that the debate about psychiatric diagnosis has entered the mainstream. There also appears to be a significant increase in the number of professional and popular books published which are critical of the diagnostic approach (e.g., Cromby, Harper, & Reavey, 2013; Davies, 2013; Kinderman, 2014; Moncrieff, 2013).The critiques are also increasingly reflected in professional guidelines. For example, the BPS DCP's recent "Guidelines on Language in Relation to Functional Psychiatric Diagnosis" (BPS DCP, 2015a) offer alternative forms of words to replace or supplement traditional diagnostic labels. It recommends usages which attempt to describe behavior and experience in nonmedical terms, and within its personal, interpersonal, social, and cultural contexts. For example, it suggests replacing "anxiety disorder" with descriptions such as "fear," "anxiety," "worry," or "extreme anxiety."

Despite the debate, support remains in many quarters for traditional psychiatric diagnosis. Much of this support is pragmatic and reasonable—many practitioners point out that, until we have workable alternatives, diagnosis serves some useful purposes. Other commentators appear unaware of the limitations of the traditional approach, and some appear to find it difficult to contemplate alternatives. A simple search of academic articles online reveals widespread use of terms such as "heterogeneous diagnoses," especially in relation to psychosis. Few authors appear to draw the logical conclusion that psychiatric diagnoses do not generally represent discrete phenomena. More worryingly, one (medically qualified) contributor to an online blog suggested that "clinicians need to communicate to each other, and even a wrong diagnosis allows them to do so" (Paris, 2013). This seems a very odd defense—it suggests not only that clinicians could allow their care to be guided by "wrong" diagnoses but also that they should share their errors with colleagues.

The Future

Proposals for radical change to mental health care continue. Both psychiatrists (e.g., Bracken et al., 2012) and psychologists (e.g., Kinderman, 2014) argue for reform; in the latter case arguing that:

> . . . services should . . . be based on the premise that the origins of distress are largely social . . . should replace "diagnoses" with straightforward descriptions of problems . . . should radically reduce use of medication, and use it pragmatically rather than presenting it as "treatment," . . . should tailor help to each person's unique and complex needs . . . and should offer care rather than coercion. Mental health teams need to be radically different . . . under local authority control, and . . . we must establish the social prerequisites for genuine mental health and well-being. (p. 191).

From a slightly different perspective, the Only Us Campaign (2015) disputes the diagnostic distinction between "well" and "ill," arguing that:

> . . . the uncomfortable truth [is] that there's a continuum, a scale along which we all slide back and forth during our lives, sometimes happy, occasionally depressed or very anxious; mostly well balanced but with moody moments; usually in touch with reality, but at times detached or even psychotic. When we separate ourselves and imagine humanity divided into two different groups, we hurt those labelled as sick, ill, even mad. We allow stigma, prejudice and exclusion to ruin potentially good and creative lives. But we also hurt ourselves, because we stress ourselves out with false smiles and the suppression of our own vulnerabilities. There is no them and us, there's only us.

As has been argued elsewhere (Cooke, 2014; Cromby et al., 2013; Kinderman, 2014), we need a wholesale revision of the way in which we think about psychological distress. We need to acknowledge that such distress is a normal, rather than abnormal, part of human life—that humans respond to difficult circumstances by becoming distressed. Such an approach recognizes that there is no easy "cut-off" between "normal" experience and "disorder," and (as suggested in the 2011 BPS statement described above) that psychosocial factors such as poverty, unemployment, and trauma are the most strongly evidenced causal factors for psychological distress (Read & Bentall, 2012).

While some people find a name or a diagnostic label helpful, our contention is that this is because of the implication that their problems are recognized (in both senses of the word), understood, validated, and explicable, and that help is available. In other words, within our current system and frames of reference, a psychiatric diagnosis is often the only way that someone in distress can have three important needs met: validation (acknowledgement that they have a significant and understandable problem for which they are not to blame), income (access to sickness pay and/or disability benefits), and support (emotional and practical support from those around them, and professional help; Cooke, 2013; Cooke & McGowan, 2013). Those of us working on developing alternatives need to bear in mind these important considerations, perhaps particularly in the current context of "austerity" measures together with cuts to public services and social security. Nevertheless, alternatives are badly needed in view of the significant problems with the diagnostic approach outlined throughout these special issues and which for many participants, motivated the campaign described here.

There are already valid and effective alternative systems for identifying and describing psychological distress that may be helpful for the purposes of clinical practice, communication, record-keeping, planning, and research, such as the operational definition of specific experiences or phenomena (Kinderman et al., 2013). For clinicians working in multidisciplinary teams, the most useful approach is that known as "collaborative formulation" (BPS DCP, 2011; Johnstone, 2014; Johnstone & Dallos, 2013). An individual formulation is a working hypothesis about the problem, which the person concerned develops in collaboration with a clinician. It consists of a summary of the individual's problems and circumstances, hypothesis about their origins and possible therapeutic solutions. This "problem definition, formulation" provides an alternative to the "diagnose and treat" approach, which has the potential to yield the same benefits without the many inadequacies and dangers of the current approach. For more about formulation, see Lucy Johnstone's article in Special Issue #2.

Of course, psychology, at least as much psychiatry, is rooted in Western notions of scientific rationalism, and just as influenced by social and political context—so in the present times, neoliberal thinking in particular. Psychology is also therefore just as vulnerable to naivety about the culturally situated and specific nature of its ideas and methodologies. Robust and insightful critique of the diagnostic model may help in this respect. In practical terms, however, care must be taken to ensure that formulations are genuinely collaborative and coproduced with clients, rather than becoming another example of something "done to" service users by professionals. A recent leaflet for the public suggests that; " . . . working on a formulation is like two people putting together a jigsaw . . . " (BPS DCP, 2015b). It is important that this is not an expert imposition of a particular scientifically and professional privileged point of view, but rather a collaborative exploration of possible explanations and solutions.

This article began with a quote from 1854. It seems fitting (in a historical account) to end with a quote from Herman Melville's (1891) unfinished novel *Billy Budd*:

> Who in the rainbow can draw the line where the violet tint ends and the orange tint begins? Distinctly we see the difference of the colors, but where exactly does the one first blendingly enter into the other? So with sanity and insanity. In pronounced cases there is no question about them. But in some supposed cases, in various degrees supposedly less pronounced, to draw the exact line of demarkation few will undertake tho' for a fee some professional experts will. There is nothing nameable but that some men will undertake to do it for pay. (p. 287)

This last point, "some men will undertake to do it for pay," is perhaps important. We started this article with a description of how social and economic factors, as much as scientific factors, appear to have influenced the development of psychiatric diagnosis. The linkage of profit, power, and status to the use of diagnosis is surely important (Whitaker & Cosgrove, 2015)—if outside the scope of this article.

So what should we do now? One direct and clear suggestion (taken from a recent book by the first author: Kinderman, 2014) is that:

> . . . services should . . . be based on the premise that the origins of distress are largely social . . . should replace "diagnoses" with straightforward descriptions of problems, . . . should tailor help to each person's unique and complex needs . . . and should offer care rather than coercion. (p. 197)

Declaration of Conflicting Interests

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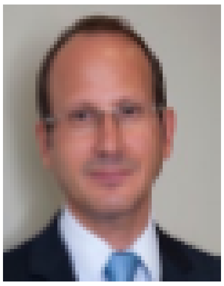
Author Biographies



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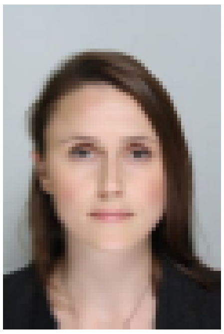

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EDITORIAL

Changing society's whole approach to psychosis

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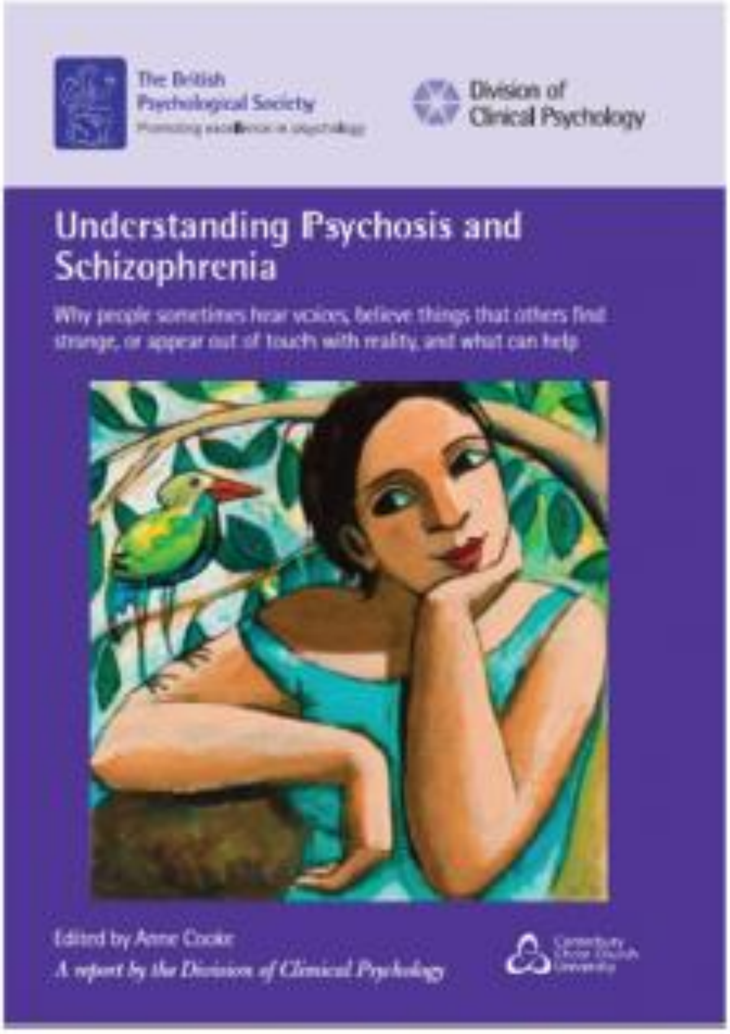

The British Psychological Society
Promoting excellence in psychology

Division of
Clinical Psychology

Understanding Psychosis and Schizophrenia

Why people sometimes hear voices, believe things that others find strange, or appear out of touch with reality, and what can help

Edited by Anne Cooke
A report by the Division of Clinical Psychology

Canterbury Christ Church University

The British Psychological Society's report "Understanding Psychosis and Schizophrenia: why people sometimes hear voices, believe things that others find strange, or appear out of touch with reality, and what can help" (Cooke, 2014) has generated extensive media coverage and debate. It is a book-length consensus report outlining in everyday language a psychosocial approach to experiences that are commonly thought of as psychosis. Written by a group of 24 authors including many of the leading psychology researchers in the field, together with people who have

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themselves experienced psychosis, it aims to provide an accessible overview of the current state of knowledge in language that everyone can understand.

In contrast to many extant public information materials that tend to argue that schizophrenia is a brain disease (e.g. University of Maryland, n.d.), but in line with the views of many contributors to this journal (e.g. Beck et al., 2012) the report outlines a psychosocial approach, arguing that even the most severe distress and the most puzzling behaviour can often be understood psychologically. It also describes psychological and social approaches to helping, exhorting professionals not to insist that service users accept any one particular framework of understanding, for example, that their experiences are symptoms of an illness. It has attracted significant attention in the UK and world media. For example, its release was covered in the UK by BBC Radio 4's “‘Today’ programme” (BBC, 2014) and in the USA by the New York Times, where it was the subject of an article entitled “Redefining Mental Illness” (Luhrmann, 2015).

The document had its origins back in 1999. A group of NHS and academic clinical psychologists were outraged at the widespread misinformation and atrocious stereotypes that were dominating media coverage at the time, particularly with respect to psychosis, with headlines like “Free to kill - lunatics left to roam streets butcher 90 people a year” (from the now defunct but then very popular *News of the World*) and people with mental health problems referred to as “walking time bombs” even in broadsheet newspapers (e.g. The Guardian, 1999). We felt that our profession had a responsibility to challenge these stereotypes, and that we had something unique to contribute as psychologists. Research into the psychology of psychosis was burgeoning, and many of its findings were challenging not only media stereotypes but also much “accepted wisdom” within mental health services as well.

For example, research was revealing that “psychotic” experiences are actually very common. Thousands of people have unusual beliefs or hear voices, but live successful lives and never come into contact with mental health services. Evidence was also accumulating that rather than being some scary mystery brain disease, psychosis can often be a reaction to the things that happen to us – for example, abuse and trauma – and the way we make sense of those events.

We summarised the latest research into one easy-to-read document aimed at service users, journalists, policy makers and the public. We hoped not only to challenge the myths, but also to provide a resource for people who might not have come across all these ideas or research studies before. In particular, believing that “information is power”, we hoped that a summary of the various debates and evidence with regard to “psychotic” experiences would be useful to service users. We wanted it to be a resource that people could draw on in their negotiations with professionals who issue advice and sometimes even use coercion on the basis of their claimed expertise. Twenty of the leading clinical psychologists in the field contributed, and in the summer of 2000 the report was published, under the now somewhat anachronistic sounding title of “Recent Advances in Understanding Mental Illness and Psychotic Experiences” (Kinderman & Cooke, 2000). Later, with a grant from the UK Government Department of Health, we produced a set of training materials, “Psychosis Revisited” (Basset et al., 2003), which became a bestseller (Basset et al., 2007; Butt et al., 2010). In 2010 the Society published a second public information report, this time about the tendency to experience extreme moods that can lead to a “bipolar” diagnosis, edited by Steven Jones, Fiona Lobban and myself (Jones et al., 2010).

In 2012 the Society's Division of Clinical Psychology asked me to lead a project to produce an updated report on psychosis, summarising the huge progress made over the intervening years in consolidating a consistently psychological approach to understanding and helping with “psychotic” experiences. Most of those who had contributed the first time were keen to be part of this new project too. There were also new contributors, many of them younger researchers who had come to prominence since the first report, for example, Tony Morrison and Daniel Freeman. Significantly, and as is now common practice with articles in this journal (e.g. Wykes & Brown, 2015), the document was co-produced with people with personal experience. Around a quarter of the contributors had themselves experienced psychosis, including some of the psychologists.

Our primary target audience is the public and those who help shape public opinion, such as journalists, as well as mental health staff, service users and their families. Available free from www.understandingpsychosis.net (with free hard copies from membernetworkservices@bps.org.uk), it is written in everyday English rather than professional language, and includes an extensive list of further resources, with web links. Swedish and Spanish versions are also now available.

Its main messages are:

- The problems we think of as “psychosis” – hearing voices, believing things that others find strange, or appearing out of touch with reality – can be understood in the same way as other psychological problems such as anxiety or shyness.
- They are often a reaction to trauma or adversity of some kind that impacts on the way we experience and interpret the world.
- They rarely lead to violence.
- No one can tell for sure what has caused a particular person's problems. The only way is to sit down with them and try and work it out. The opportunity to talk things through in this way is vital, but surprisingly rare. Psychological therapy needs to be available to everyone who is distressed by “psychotic” experiences.
- Services should not insist that people see themselves as ill. Some prefer to think of their problems as, for example, an aspect of their personality which sometimes gets them into trouble but which they would not want to be without.
- We need to invest much more in prevention by attending to inequality and child maltreatment. Concentrating resources only on treating existing problems is like mopping the floor while the tap is still running.

The implications of this analysis for services are significant. For example, although medication has a place, the emphasis shifts from “waiting for the meds to work” to helping each person to make sense of their experiences and to find the support that works for them. Perhaps one day the default approach in psychosis services will be a psychological one, with a psychological formulation driving every decision and the content of every conversation. We hope that our document will also contribute to a change in attitudes, challenging "them and us" thinking. Rather than being stigmatised and seen as somehow alien (see https://www.talkforhealth.co.uk/the-only-us-campaign/), people who experience psychosis should find those around them accepting, open-minded and willing to help.

The press coverage was very encouraging, as was the support from other professional bodies and mental health charities. Those welcoming the report from the London launch platform included the President of the UK Royal College of General Practitioners, Professor Mike Pringle, Professor Sir Robin Murray from the Royal College of Psychiatrists and National Clinical Director for Mental Health Services, Dr Geraldine Strathdee, together with the Shadow Government Minister for Mental Health, Luciana Berger MP and representatives from the major mental health charities (Gilchrist, 2015).

Even more encouraging, for me personally at least, has been the overwhelmingly positive response from people who have themselves experienced psychosis or used mental health services (e.g. Allan, 2014, Hearing Voices Network, 2014). For example, carer and survivor Nicky Hayward (n.d.) described her decades of contact with mental health services, adding "at any time over all these years I'd have done anything to have been given a handbook like this!" Eleanor Longden, a contributor to the report and a psychologist who was herself diagnosed with schizophrenia in the past, also commented how different things would have been for her had the report been around at the time she was hospitalised (personal communication, 2014). Many other people have emailed or tweeted to say that our document has made a profound difference to them. After years of working all hours on it, these responses have been profoundly moving.

Unsurprisingly, given its high profile and its challenge to the status quo, the report has not been without its critics, particularly in the USA. For example, in response to the New York Times coverage, former President of the American Psychiatric Association, Jeffrey Lieberman donned a white coat and posted a personal video blog entitled "What Does the New York Times Have Against Psychiatry?" (Lieberman, 2015). In it he accused us of "challenging the veracity of diagnoses and giving people . . . license to doubt that they may have an illness". Some commentators (e.g. May & Svanholmer, 2016) have seen such responses as a sign that the report's normalising message might be a threat to those whose work has been based on the idea of brain diseases requiring aggressive pharmacological treatment. In a similar vein, some other US psychiatrists, for example, Allen Frances have suggested that the report does not address "real" schizophrenia (Frances & Cooke, 2014).

Others have suggested that the report "ignores a hundred years of psychoanalytic thought" (Ferraro, 2014). Some criticisms have been more technical, for example, those of our handling of the issue of comparisons between psychological therapies on the one hand and medication on the other. These have been addressed in traditional academic outlets (e.g. Kinderman et al., 2015).

Some criticisms are well taken. For example, people have pointed out (e.g. Fernando et al., 2014) and we have acknowledged (e.g. Cooke et al., 2015), that the report paid insufficient attention to the specific issues faced by people from black and minority ethnic groups. People from these groups experience discrimination not only within society but within services, and are overrepresented at the "sharp end" of psychiatry: more likely to be diagnosed with schizophrenia, more likely to experience compulsion and forced medication, less likely to be offered talking therapy. A revised version with improved sections on racism and inequality will be available in due course.

Some (e.g. Ferraro, 2014) have painted the report as an attempt by psychologists, and specifically proponents of CBT for psychosis, to "sell their wares". Although, of course every statement by a professional body contributes to public awareness of what the profession has to offer, our primary motivation was very different. The report is at pains to acknowledge that "often the most important source of help and support is our network of relationships: friends, family and community": self-help is discussed before that offered by professionals. And far from claiming that psychologists – or indeed any "experts" – have all the answers or know what is best for people, the report suggests that "people themselves are the best judges of whether a particular therapy or therapist is helping them" (p.84). It advocates humility on the part of professionals, suggesting that the common idea that our job is to tell people what they need should be replaced with a different "guiding idea":

"Mental health is a contested area. The experiences that are sometimes called mental illness, schizophrenia or psychosis are very real. They can cause extreme distress and offering help and support is a vital public service. We know something about the kinds of things that can contribute to these experiences or cause them to be distressing. However, the causes of a particular individual's difficulties are always complex. Our knowledge of what might have contributed, and what might help, is always tentative. Professionals need to respect and work with people's own ideas about what has contributed to their problems. Some people find it helpful to think of their problems as an illness but others do not. Professionals should not promote any one view, or suggest that any one form of help such as medication or psychological therapy is useful for everyone. Instead we need to support people in whatever way they personally find most helpful, and to acknowledge that some people will receive support partly or wholly from outside the mental health system" (p.103).

Declaration of Interest

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They're NICE and Neat, but Are They Useful? A Grounded Theory of Clinical Psychologists' Beliefs About and Use of NICE Guidelines

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Guidelines are ubiquitous but inconsistently used in UK mental health services. Clinical psychologists are often influential in guideline development and implementation, but opinion within the profession is divided. This study utilized grounded theory methodology to examine clinical psychologists' beliefs about and use of NICE guidelines. Eleven clinical psychologists working in the NHS were interviewed. The overall emerging theme was; NICE guidelines are considered to have benefits but to be fraught with dangers. Participants were concerned that guidelines can create an unhelpful illusion of neatness. They managed the tension between the helpful and unhelpful aspects of guidelines by relating to them in a flexible manner. The participants reported drawing on specialist skills such as idiosyncratic formulation and integration. However, due to the pressures and dominant discourses within services they tended to practice in ways that prevent these skills from being recognized. This led to fears that their professional identity was threatened, which impacted upon perceptions of the guidelines. To our knowledge, the theoretical framework presented in this paper is the first that attempts to explain why NICE guidelines are not consistently utilized in UK mental health services. The current need for services to demonstrate 'NICE compliance' may be leading to a perverse incentive for clinical psychologists in particular to do one thing but say another and for specialist skills to be obscured. If borne out by future studies, this represents a threat to continued quality improvement and also to the profession. Copyright © 2016 John Wiley & Sons, Ltd.

Key Practitioner Message

- Guidelines have many benefits, but the current pressure for services to be 'NICE compliant' may be having unintended negative as well as positive effects.
- Lack of implementation may be partly the result of active choice by clinicians concerned to use the full range of professional skills and to offer flexibility and choice to service users.
- The current context is creating a perverse incentive for clinicians to say one thing but do another. This is problematic for services and a potential threat to the profession of clinical psychology.

Keywords: NICE, Clinical Guidelines, Decision Making, Clinical Psychologists, Mental Health

Numerous authors have highlighted the increasing role of clinical practice guidelines in both physical and mental healthcare over the last two decades (e.g., Franx, 2012; Girlanda, Fiedler, Ay, Barbui, & Koesters, 2013; Grimshaw *et al.*, 2004; Nathan, 1998; Parry, Cape, & Pilling, 2003; Pilling, 2008; Woolf, Grol, Hutchinson, Eccles, & Grimshaw, 1999). Parry *et al.* (2003) suggested that 'health care professionals are living in the age of evidence-based guidance' (p. 337), highlighting a 'remarkable proliferation of clinical practice guidelines' (p. 337).

The National Institute for Health and Care Excellence (NICE) was established in 1999 to produce guidance for health professionals working in the UK National Health Service (NHS). The aim was to improve clinical effectiveness and reduce variations in practice across NHS Trusts (Department of Health (1998)). There is evidence that the level of implementation of NICE guidelines in UK mental health services is low (e.g., Court, 2014a; Haddock *et al.*, 2014; Mears, Kendall, Strathdee, Sinfield, & Aldridge, 2008).

Berry and Haddock (2008) highlighted the paucity of research into factors affecting the use of NICE guidelines

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in UK mental health services and stressed the need for such research. A number of studies have since been published. In relation to NICE guidelines for mental health conditions, research has investigated adherence to guidelines in UK services by: GPs, (Gyani, Pumphrey, Parker, Shafran, & Rose, 2012; Gyani, Shafran, & Rose, 2011; Toner, Snape, Acton, & Blenkiron, 2010), care co-ordinators (Prytys, Garety, Jolley, Onwumere, & Craig, 2011; Sin & Scully, 2008), community mental health teams (Michie *et al.*, 2007; Rhodes, Genders, Owen, O'Hanlon, & Brown, 2010), psychiatrists and paediatricians (Kovshoff *et al.*, 2012) and counselling psychologists (Hemsley, 2013).

The significance of external factors, such as resource problems, has been a consistent finding across the existing studies. Both positive and negative views regarding NICE guidelines have been reported, with particularly rich data emerging from studies utilising qualitative methodology (e.g., Kovshoff *et al.*, 2012; Prytys *et al.*, 2011). However the quality of the qualitative studies has been variable, with reflexivity not always clear (e.g., Hemsley, 2013) and researcher allegiances sometimes appearing to impact on interpretations. In particular, some studies (notably Michie *et al.*, 2007 & Prytys *et al.*, 2011) appear to assume from the outset that the aim should be to increase implementation of guidelines, rather than taking a position of exploring the advantages and disadvantages of guideline usage. Furthermore, many of the existing studies (e.g., Michie *et al.*, 2007; Prytys *et al.*, 2011; Rhodes *et al.*, 2010) based findings on a small sample of participants from a variety of professional backgrounds. It seems likely that different professions will vary on their beliefs about and knowledge of NICE guidelines as a result of their differing amounts and types of training and varying professional identities.

There have been no studies to date focusing on clinical psychologists' (CPs) beliefs about and use of NICE guidelines. CPs play important roles in multidisciplinary teams in terms of: providing psychological therapies, consuming and disseminating new research, teaching, assisting others to work in psychologically informed ways and carrying out local audits. They are influential in contributing to the design of new services and the development of existing ones (e.g., Care Services Improvement Partnership, 2007). It could therefore be argued that CPs have a leading role to play in relation to NICE guideline adherence.

Many CPs appear to be in favour of NICE guidelines (The British Psychological Society (BPS), 2007); numerous CPs have contributed to their production, and the BPS has co-published some guidelines, for example the schizophrenia guideline (The National Institute for Health and Clinical Excellence, 2010). However, many have also questioned their usefulness (e.g., Adams, 2008; Barkham, 2007; Fairfax, 2008; Hammersley, 2009; McGowan, 2009; Mollon, 2009a, 2009b; Nel, 2011; Smail, 2006; The Midlands Psychology Group, 2010). Smail (2006) suggested that CPs are 'selling [their] soul' (p.17) by not challenging NICE guidelines. Mollon (2009b) argues that the fact that 'psychologists, and the BPS, have colluded in this betrayal of our profession through an endorsement of the crude medical model of NICE is deeply puzzling—a phenomenon that itself deserves careful study' (p.130).

AIMS

Eccles, Grimshaw, Walker, Johnston, and Pitts (2005) suggest that research into the use of clinical practice guidelines would benefit from drawing upon psychological theory in order to help understand the beliefs and behaviour of clinicians. However, psychological theory has not been utilized to any great extent in the existing evidence base (Michie *et al.*, 2007, being a notable exception). The current study attempted to generate new psychological theory, producing a theoretical framework which might help explain how NICE guidelines are utilized and which factors might impact upon this.

As researcher allegiance has been an issue in previous research, it was felt important that this study aimed only to examine, rather than to promote or dispute the use of guidelines. It was hoped that this approach would allow full exploration of the benefits and limitations of guidelines and how CPs manage their use in practice.

It was felt that CPs were a particularly important profession to investigate. They are important members of UK mental health services, and their use of NICE guidelines has not been investigated. Furthermore, there appear to be conflicting views within the profession with respect to the guidelines.

RESEARCH QUESTIONS

This study attempted to address the following questions:

i What beliefs do CPs hold about NICE guidelines?
ii How do CPs describe their use of NICE guidelines?

METHOD

Design Overview

Semi-structured interviews were conducted with 11 CPs and the information that emerged was analysed using grounded theory methodology (Charmaz, 2006). Grounded theory enables a researcher to develop a theory from ('grounded in') the data, rather than seeking evidence to support an existing theory (Willig, 2001). This makes the method particularly helpful in areas lacking existing theory, such as this one. This study utilized Charmaz's (2006) social constructivist approach which acknowledges the role of both researcher and participants in co-constructing the knowledge that emerges from study.

Ethical Considerations

This study was approved by a review panel and ethics committee at Canterbury Christ Church University. The Research and Development departments of three English NHS trusts provided permission for their staff to take part in this research. Participants were fully informed of the purpose of the study. The principal researcher (first author) endeavoured to maintain a stance of independence and curiosity in the interviews. It was hoped that this would allow participants to speak freely.

Participants

Participants were CPs in routine practice in the NHS. CPs who had published views about NICE or had been involved in guideline production were excluded, as their positions already appeared clear. Information about the study was circulated within Trusts: participants either responded to recruitment emails ($n = 7$) or were known to the first author ($n = 4$). No current colleagues were recruited in order to ensure that working relationships did not impact upon the research. Participant characteristics are presented in aggregated form (Table 1) to help protect anonymity.

Procedure

Interviews ranged from 45 to 72 min and adopted an open questioning style. In line with the recommendations of Glaser (1998) and Charmaz (2006), there was no preconceived interview schedule. All interviews began with an open question simply asking the participant to share their thoughts on NICE guidelines. The interviewer (first author) then attempted to follow the participants' lead, making a concerted effort to try to understand their point of view and actions (Charmaz, 2006). This helped 'enter the participants' world' (Charmaz, 2006, p.19) and limit the influence of the researchers' pre-existing beliefs, assumptions and allegiances on the data (Holton, 2007).

Interviews were audiotaped and then transcribed. The first three interviews were analysed using line by line coding followed by focused coding (Charmaz, 2006). The subsequent transcripts were analysed using focused coding. Tentative categories and subcategories were then formed, attempting to seek an 'underlying logic of apparently disparate events' (Dey, 2007, p.188). Throughout this process, theoretical memos were kept in a research diary, reflecting on the process and on possible emerging themes (Charmaz, 2006).

Similarities and differences between the views of participants were explored through constant comparison (Glaser & Strauss, 1967). Theoretical sampling (Glaser & Strauss, 1967), with the assistance of a pre-interview questionnaire (Appendix M of Court, 2014b), helped ensure that participants with a variety of opinions were recruited. In latter interviews, participants were asked questions influenced by the analysis to date (Morse, 2007). Emerging codes and categories were constantly compared, testing their validity (Holton, 2007).

The cyclical process of data collection, analysis, theoretical sampling, theoretical categorisation and then further data collection continued until 'theoretical sufficiency' (Dey, 1999) was judged to have been achieved. This is the point at which the emergent theory is considered by the researchers to have good explanatory power and no significantly novel information is deemed to be emerging from additional data collection. Unlike 'theoretical saturation' (Glaser & Strauss, 1967), there is no claim that the process has been exhaustive, an aim which Dey (1999) argues is often unrealistic. This stage was reached after 11 interviews. This sample size is typical for a qualitative study of this kind (Adler & Adler, 2012).

Quality Assurance

It is acknowledged that qualitative analysis is inevitably influenced by the researchers' views and standpoint (Charmaz, 2006). As such, numerous steps were taken to ensure reflexivity and transparency. As recommended in all qualitative research, a research diary (Appendix L of Court, 2014b) was completed throughout the study, to

Table 1. Participant characteristics

Gender	9 women, 2 men
Speciality	6 adult mental health, 2 child and adolescent mental health, 1 learning disabilities, 1 forensic, 1 older people mental health
Band	2 band 7, 5 band 8a, 1 band 8b, 3 band 8c
Country of training	10 were trained in the UK
Years since qualifying	Range 2 – 21. Mean 8.2. Standard deviation 5.8.
Preferred therapeutic modality	3 Cognitive Behaviour Therapy (CBT), 5 Integrative, 2 Cognitive Analytic Therapy and 1 'Psychodynamic, Systemic and CBT'.

help think through emerging ideas and to give readers a window into this process (Watt, 2007).

To further aid the process of reflexivity, a bracketing interview (Rolls & Relf, 2006) was conducted between the principal researcher (first author) and lead supervisor (second author). This aimed to explore the impact of the researcher's assumptions and experiences on the research (reflections from this interview are available in Appendix O of Court, 2014b). Furthermore, coding and category development was regularly checked between the study authors and also within a grounded theory discussion group made up of other researchers (all trainee clinical psychologists) completing grounded theory studies. Detailed examples of quality assurance, reflexivity and transparency are available (Court, 2014b).

RESULTS

Figure 1 presents a model of the clinical psychologists' beliefs about NICE guidelines, how they report drawing on them in their practice and the relationships between the two.

Model Summary

The CPs acknowledged that NICE guidelines have to be seen in the context of the current climate of limited resources. The overall emerging theme was 'considering NICE guidelines to have benefits but to be fraught with dangers'. The guidelines were seen as a useful guide to the evidence base, and the power of NICE endorsement for psychological interventions was valued. However, the CPs worried that the guidelines can create an illusion of neatness which is unhelpful in the context of the complexity of clinical practice in the NHS. All of the CPs valued individualized, collaborative, formulation-driven interventions and saw this approach as sitting uneasily with the use of guidelines. Nevertheless, they experienced a pressure to use them.

This tension led CPs to use guidelines flexibly. Some CPs ignored them. Others drew on them selectively according to the needs of the individual client, emphasising that they are guidelines rather than instructions. However, the need to be seen to follow guidelines had the perverse effect of leading participants to act in ways that obscured their particular skills as CPs. Some reported concealing the details of their practice from managers. Often, they would use a range of psychological theory to inform a tailored, formulation driven intervention but then label it as if it were a unimodal, diagnosis driven treatment, for example 'CBT for depression'. The majority of participants were very wary of guidelines for this reason, and saw them as a threat to their professional identity and indeed to the future of the profession. Full details of the coding and categories are presented elsewhere (Court, 2014b). The key findings are presented here, together with direct quotes to ensure that the analysis 'stays close to the data' (Charmaz, 2006, p49). Participant names have been changed to protect confidentiality.

NICE Guidelines Have Benefits

The CPs saw benefits in NICE guidelines and viewed them as a useful guide to the evidence base.

> *They provide a framework and an overarching knowledge base which summarises research in that particular area. And I think that's a great strength, you know, if you don't have to go through millions of literature searches to get at the same thing, NICE have done it for you. (Catherine).*

Endorsement by NICE was seen as helpful in improving access to psychological treatments:

> *…access to psychological therapies for people with a diagnosis of schizophrenia has really increased as a result of NICE guidelines. (Sam).*

NICE Guidelines Can Create an Unhelpful Illusion of Neatness

The CPs highlighted problems with the diagnostic system on which NICE guidelines are based.

> *You could pick apart the whole thing potentially on the basis of questioning the validity of diagnosis. (Morgan).*

Participants questioned NICE's reliance on randomized controlled trials (RCTs), arguing that such trials do not represent the complexity of routine practice.

> *A lot of them are based on like RCT's where somebody has to have pure depression in their sample in order to carry out the research. But, realistically, I mean that's always a limitation of RCT's in that it doesn't paint an accurate picture of the kind of client groups you're actually dealing with. (Catherine).*

CPs worried about the dominance of CBT in the NICE guidelines, suggesting that it has been oversold and might fall out of favour.

> *There could be a bit of a ticking timebomb a little bit that erm, over time I think managers and other kind of commissioners and people will begin to realise that CBT isn't this magic curing thing. (Amy).*

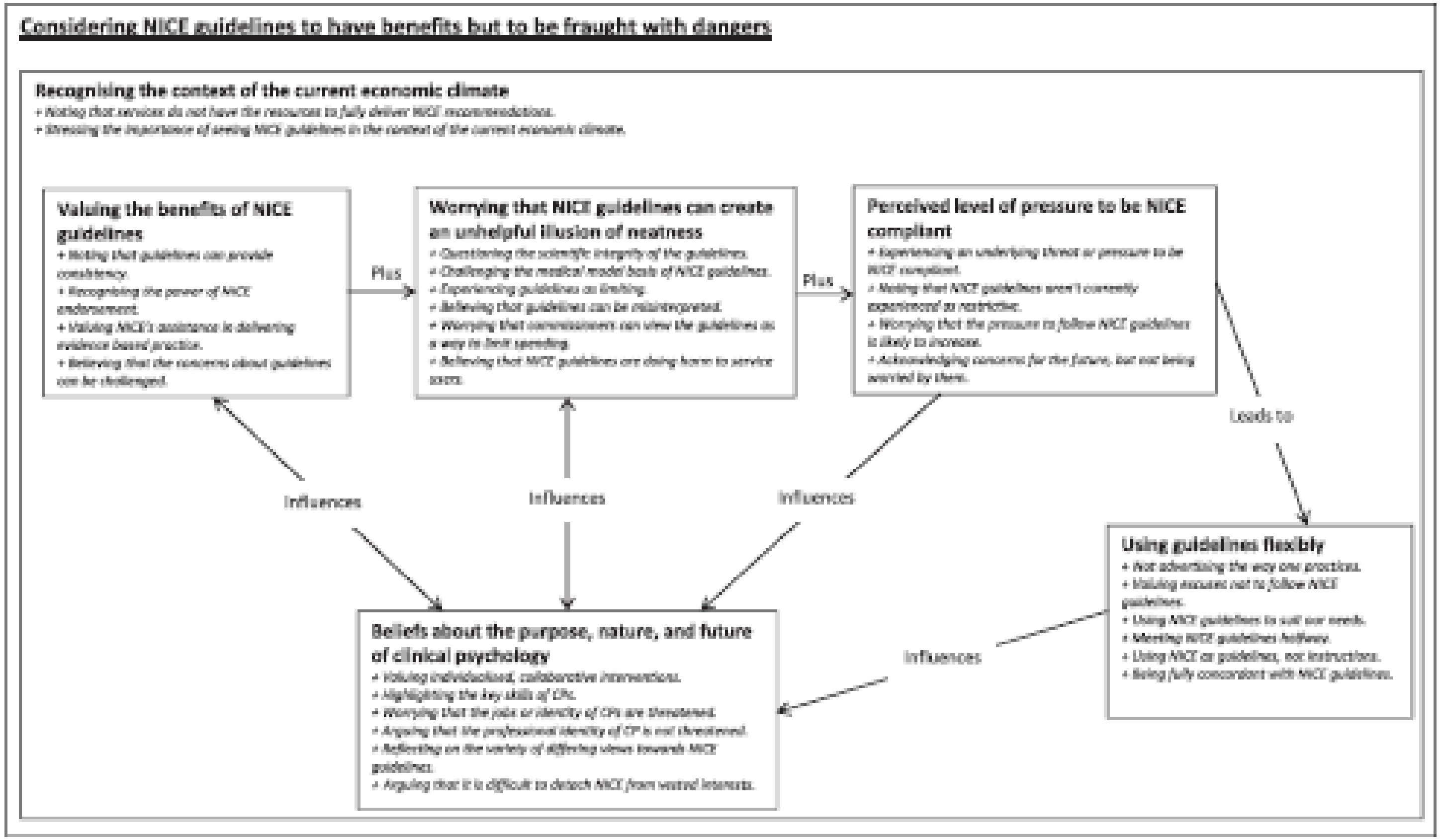

Figure 1. Model conceptualising the clinical psychologists' beliefs about and use of NICE guidelines

The guidelines were seen as privileging CBT over other therapeutic approaches and this was linked to the use of diagnostic categories and medical concepts and language in CBT research.

> *I think CBT also fits very nicely because it's the most medical of the erm therapies I think, and so I think it's attractive to psychiatrists and other professionals who can understand then, when it's in units, isn't it, it's almost like so many sessions is almost like a dose, of how much medication you need, erm, so it is, it's easy to communicate what psychology does if it's all languaged in this way. (Amy).*

CPs noted that the issue of outcome measurement was complicated in therapies with different philosophical underpinnings and that this might have contributed to their relative absence from the guidelines.

> *I can't imagine some, one of the more traditional existentialist therapies like Yalom-based therapy, getting NICE backing because how they would define whether the therapy is working isn't immediately measurable, and it's that question of how measurable it is. (Paul).*

Participants were concerned that if particular approaches were not backed by NICE then their development would be neglected.

> *Our Trust, for instance, has got lots of training programs that have been developed over the last few years in various things like IPT, EMDR, MBCT, CBT, all the therapies that are in the NICE guidelines and only the therapies that are in the NICE guidelines. (Morgan).*

This concerned CPs as they saw value in other modalities.

> *So obviously a lot of the NICE guidance, CBT is the recommended line of treatment… But I think that is to the detriment of the other types of work which can be incredibly effective for a lot of people. (Catherine).*

The CPs wanted NICE to acknowledge the difficulty in measuring psychological therapy.

> *I think NICE needs to realise that psychological therapies are not like medication and you can't evaluate them in the same way, you need a broad range of evidence. (Sam).*

The CPs worried that NICE guidelines could be misinterpreted by those with power but with little understanding of the complexities of clinical practice.

> *I think there's a danger that erm, policy makers, erm, might not have the sort of full background understanding or the critical thinking that is necessary to assess the guidelines, and they might prescribe pathways for services that are too restrictive. (Ronda).*

Bearing in mind the concerns, there was a belief that NICE guidelines were doing harm to service users.

> *This feels like research that needs to be picked up and be ongoing, because with best intention NICE are doing harm. That is the bottom line. (Jan).*

Pressure to be 'NICE Compliant'

Most participants felt pressured to comply with NICE guidelines. Some experienced this as a threat.

> *Yeah, yeah it can feel quite threatening actually, that there's almost an undercurrent of, of threat that if we're not doing what the NICE guidelines say, erm, erm, then we won't be commissioned, because I think NICE is quite a powerful force, and I think that erm, it does have an influence on everyday clinical practice definitely. (Amy).*

There were concerns that NICE guidelines might be used in a more controlling manner in the future.

> *… that will get tighter and tighter as we move to payment by results and being commissioned to do… much more specific kind of commissioning for specific things. Specific problems using specific approaches… this is going to come to, closer and closer focus. (Morgan).*

Using Guidelines Flexibly

The CPs described a number of ways in which they managed the helpful and unhelpful aspects of the guidelines. Some CPs simply ignored them.

> _Okay. Erm, well, I don't use them. I can feel the pressure from my service and my managers and erm, it's in the water, isn't it. It's in the general culture now. But you know, I do *******[1] with all kinds of people who fall outside of what NICE say I should be using. I do ******* with all kinds of people. I use other approaches that aren't in the NICE guidelines at all. Er, I do what I see to be effective. I'm not against evidence-based work. I think it's important to evaluate what you're doing in different ways_

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[1] Therapy label omitted in the interests of confidentiality.

> *and I do that. I wouldn't want to continue doing something that clients were telling me was not helping but I don't feel I need NICE guidelines to do that. (Morgan).*

Some CPs avoided talking about aspects of their practice due to a conflict between what they believed was a helpful way to practice on the one hand, and the pressures and dominant discourses within their services on the other.

> *Well I, well I certainly wouldn't advertise what I do to the managers. (Amy).*

For example, they sometimes described what they were offering as 'CBT' even where they felt this label did not adequately or accurately reflect it.

> *I would probably say I'm doing CBT, even if I'm not doing, you know, even if it's a bit fudgy around the edges. (Jenny).*

Some participants described using guidelines selectively as a 'rhetoric of justification' for practices that they believed were helpful.

> *Well, it supports EMDR, but the CBT therapists will discount that, just as I discount the CBT promotion…Yes. That's the problem is that we actually use it to suit ourselves. Yeah, I do. (Pause, then laughs) If it was more grounded in reality, it would be a good thing. But it doesn't feel like it. It feels like I can just pick it up and drop it down as it suits me. So I use it to suit my own ends. (Jan).*

> *So, it's almost as if, the, erm, the fact that something features in NICE is your kind of political doorway into, into the er heavenly realms. And you know, once you're in, you know, you can kind of play around a bit, kind of thing. But if you don't have the key to that door, you're not in the NICE guidelines, you can't really start. It's a bit of a fudge, I think, because people are trained on the basis that this therapy is NICE approved, but they're then ending up doing it with groups of people that would not be NICE approved. (Morgan).*

CPs frequently referred to the fact that guidelines are just that, guidelines, rather than being prescriptive.

> *For me, they're guidelines, rather than somebody telling me what to do. (Kim).*

Other CPs ensured that they were seen as NICE concordant through integrating wider psychological ideas into CBT.

> *You can integrate—I quite often make use of psychodynamic or systemic ideas which I might, you know, bring into my CBT work…which I think is perfectly fine within a CBT model. (Sam).*

The participants stressed the ability of CPs to understand the underlying principles of therapies and make adjustments rather than following manuals.

> *You have to adapt what you do. But I think when you make those adaptations you have to be familiar with the manualised treatments and the kind of things that have been evaluated in RCT's, and you have to know that stuff and you have to understand the underlying principles so that when you make those adaptations you don't, you remain true to the principles of the treatment. (Sam).*

There was a desire for NICE to apply its principles to itself and evaluate both its underlying assumptions and the effectiveness of its methods.

> *I think the main criticism at this stage is that it really ought to be under review, and maybe NICE should apply its own methodology to itself. And so what is the evidence base for the diagnostic system? And what is the evidence base for, you know, producing guidelines using a diagnostic system that itself isn't evidence based? (Sam).*

> *I think it deserves further research. So perhaps I would say that I'm not sure that it should be there, I'm not sure it shouldn't be there. I think it needs to be absolutely reviewed. (Jan).*

Beliefs about the Purpose, Nature and Future of Clinical Psychology

Participants worried that because of the political forces at play, CP's skill base is being obscured and there is a risk of being replaced by single-model therapists with less training who are perceived as cheaper.

> *NICE guidelines do put psychological interventions on the map… but there's a danger then, that it's erm, we're not fully understanding the scope of what psychological interventions offer, that it's not just CBT, because then there is the risk that the Trust will just, erm I guess get rid of erm clinical psychologists who are expensive to train and to employ, and just employ CBT therapists… when in reality when you're doing a piece of work, which might be CBT orientated, as a clinical psychologist I will be bringing in lots of different therapy kind of techniques and models and formulations from different erm models of psychological therapies, so I don't think it's as purist as maybe NICE guidelines might encourage people to think. (Amy).*

CPs were keen to differentiate themselves from single modality therapists.

> *I think there is a world of difference between somebody who is a trained CBT therapist and somebody who's a clinical psychologist who does CBT. (Sam).*

It was acknowledged that it can be difficult to explain what CPs do.

> *Maybe we should be better at explaining what clinical psychologists do, coming back to the sense of how do we evidence what we do? You know, and I think that's fair enough. I think that's a good question for us as a profession really, isn't it? (Kim).*

A significant theme was CPs' knowledge of a range of psychological theory, and their ability to draw on those 'first principles' flexibly to design and adapt a tailored intervention for each service user rather than following a manual. They felt that this sat ill with the widespread approach adopted by NICE of dividing both problems and interventions into fixed categories.

> *I think it's much harder to say, now, that we're working in a sort of eclectic or integrative way. When I first qualified that was really common, and I don't hear that so much anymore. (Jenny).*
>
> *It's (integration) seen as weak or a criticism, and actually I think that's our biggest strength, and that's what I mean by we're shooting ourselves in the foot. As psychologists it would be nice if we actually worked to maintain our identity and what we have that's special to offer. (Jan).*

A split was highlighted between CPs who are researchers and those who are clinicians. It was suggested that CPs who contribute to the development of NICE guidelines may have different viewpoints to CPs in routine practice.

> *Maybe they're more in their ivory towers, as people call it, doing their research, you know, rather than being on the frontline seeing how things actually are. (Sophie).*
>
> *Well I think some of the researchers who I'm thinking about, they do work in very sort of specialised centres, and they would then see that kind of patient group who might be also eligible for their studies… so, it might be that their clinical world is nice and neat like their research work, because it's a very specialised service. (Ronda).*

All of the CPs were keen to stress the importance of interventions being collaborative, individualized, and based on a human relationship between client and therapist. They worried about this becoming lost in the current context.

> *I think it would be a very worrying position to be in if psychologists did think that there was a ch-ch-ch-ch-ch, a do this, do this, do this, and that would be okay. I think that fundamentally misses the point about engaging with another person on a collaborative level, to genuinely understand what it is that they're experiencing. (Sophie).*

DISCUSSION

This study is the first to produce a theoretical framework conceptualising beliefs about and use of NICE guidelines in UK mental health services. CPs acknowledge that the guidelines have benefits, including better access to research evidence for clinicians and to psychological therapies for service users. However, participants in the current study also saw them as fraught with dangers. These included reification of psychiatric categories and psychological 'treatments', and promotion of a technocratic mind-set. Participants were also concerned that increasing reliance on guidelines, particularly by managers and commissioners without specialist knowledge, could devalue both CPs' particular skills and the importance of listening to and collaborating with individual service users. They used a number of strategies to manage the tension between the helpful and unhelpful aspects of guidelines. In particular, participants described drawing on specialist skills that go beyond the guidelines—for example a collaborative, integrative approach to therapy based on an individualized idiosyncratic formulation and informed by a range of psychological theory—but not reporting this to managers.

Knowledge

Previous studies of guideline adherence among clinicians have focused on clinician knowledge, clinician beliefs and external factors such as resource availability (Cabana et al., 1999). A number of research studies have been based upon the assumption that a greater knowledge of the content of guidelines would increase adherence (Gyani et al., 2011; Gyani et al., 2012; Rhodes et al., 2010). Participants in the current study, however, were all aware of the guidelines. Indeed, some participants even suggested that blind adherence to guidelines could sometimes follow from lack of knowledge, for example about their limitations or underlying assumptions, on the part of colleagues and managers. In the current study, adherence appeared to be more related to the other two factors, namely resources and beliefs.

Resources

Participants consistently pointed to the current economic and service context as a limiting factor in guideline implementation, suggesting that services do not have the resources to deliver all the recommended interventions. This echoes the findings of other recent UK studies (e.g., Gyani *et al.*, 2012; Michie *et al.*, 2007; Prytys *et al.*, 2011; Rhodes *et al.*, 2010).

Beliefs

Clinician beliefs as outlined above, and particularly beliefs about the nature of distress and helping appeared to be key. Whilst participants saw benefits in guidelines, their reservations were similar to those expressed in published critiques (see reviews by Court, 2014a; The UK Council for Psychotherapy, 2011). This suggests that the points made in the latter are not just the views of the disgruntled few who choose to publish their opinions, but may be widespread concerns. In particular, participants were concerned that in the current political context, adherence to guidelines will become increasingly mandatory rather than advisory. They also pointed to the danger of psychiatric categories and also specific approaches to helping becoming unhelpfully reified. The following section examines these concerns, concluding that they appear to be justified in the current context.

Guidelines or Prescriptions?

Many of the participants to this study worried that the introduction of 'Payment by Results' (Department of Health, 2002) would lead to NICE guidelines being utilized in a more prescriptive fashion. The Department of Health (2013) states that care packages will not be nationally mandated, to allow flexibility in meeting people's needs. However, it also notes that many organisations provide certain 'core interventions' based on NICE guidance to everyone allocated to a particular service 'cluster'. Increasingly, organisations mandate from the outset which approach should be used. The model of generic mental health services employing professionals with a broad training, able to draw on theoretical first principles to provide individualized treatment based on a collaborative formulation, is increasingly being replaced by one of model-specific services employing therapists with a shorter training in one, NICE-approved model only, offering predetermined, often short, packages of care to people with a particular diagnosis (Cooke & Watts, 2016). Commentators have linked this development to the current dominance of 'naïve modernism' in the intellectual sphere (Bohart & House, 2008; van Ooijen, 2011), an anxiety-driven quest for 'safe certainty' on the part of clinicians and managers (Court, 2014b; Mason, 1993) and in the political sphere of market capitalism, 'austerity' measures and privatisation of public services (Cooke & Watts, 2016).

Specific Issues for Clinical Psychology

The tensions expressed by participants of this study reflect those for the profession as a whole. CPs have been active in contributing to the development of guidelines (and of 'evidence based practice' more generally) and in advocating for their implementation (Marks, 2015). However, many vocal critics have also been CPs (e.g., Mollon, 2009a, 2009b; Nel, 2011; Salkovskis, 2002. See Court, 2014a for a review).

On the one hand, participants valued the powerful endorsement that NICE can provide to psychological therapies. They sometimes even presented work as NICE-concordant (for example, as CBT) when the reality was more complex. This can be read in a number of ways. On the one hand, it can be seen as an idealistically motivated attempt at 'systemic eloquence' (Oliver, 1996) using the dominant discourse as a resource in the service of clients (Green, 2014). On the other, it can be read as an example of personal or political self-interest. Pilgrim (2010) argues that CPs 'collude' with the dominant medical model in an attempt to gain status.

One striking finding from the current study was the perverse incentive within the current system for CPs to claim to be doing protocol-driven, single-model therapy whilst actually conducting much more sophisticated interventions, drawing on a range of psychological theory and based on an individualized formulation co-constructed with the service user. Mowbray (1989, 2009) describes the ability to conduct such interventions as 'Level 3 skills', suggesting that they are what differentiate CPs from the therapists who provide 'Level 2' protocol-driven interventions. In a context where CP posts are already being replaced with cheaper 'CBT therapist' or 'Psychological Wellbeing Practitioner' posts (Marks, 2015), this perverse incentive may therefore represent a significant threat. There is an urgent need for CPs to articulate and demonstrate the value of their particular skills. A recent chair of the Division of Clinical Psychology, Pemberton (2014) acknowledged the challenge for CPs to justify their cost and demonstrate their worth, noting that in many areas posts are being downgraded and CPs losing influence. The CPs in this study were keen to differentiate themselves from single modality therapists, even noting that CBT by a CP is different to CBT by a CBT therapist. There is empirical evidence to support this claim, with CPs scoring higher than CBT therapists when their CBT interventions were compared through blind rating (Brosan, Reynolds, & Moore, 2007; McManus, Westbrook, Vazquez-Montes, Fennell, & Kennerley, 2010).

Clinical Implications

The current findings point to the importance of allowing skilled clinicians flexibility in what they offer clients. This sounds common-sense but appears to be increasingly under threat, with some services prescribing not only the 'brand' of therapy offered but requiring clinicians to work to protocols for each 'diagnosis' and specifying the number of sessions (Cooke & Watts, 2016; Rhodes, 2016). Greater flexibility would arguably not only be more satisfactory for service users, some of whom have complained about poor care resulting from unthinking adherence to protocols (Hamilton *et al.*, 2011) but is likely to be more efficient overall (the most effective intervention is the one that is right for the individual) and could help ameliorate the current high levels of stress and sickness absence among therapists (Rhodes, 2016).

Participants to this present study suggested that NICE should be reviewed, including the process by which guidelines are created, the assumptions on which they are based (such as the validity of diagnostic categories), the way that psychological therapy is measured and recommendations about implementation.

Research Implications

First, it would be interesting to repeat this study with members of professions other than clinical psychology.

Second, it seems important to develop therapy research methodologies that do not depend on manualisation of particular 'therapy packages' (Barkham, 2007; Barkham, Hardy, & Mellor-Clark, 2010; Parry *et al.*, 2003; The Division of Clinical Psychology, 2011). Examples might include case studies (e.g., Stenhouse & Van Kessel, 2002), therapy process research (The Division of Clinical Psychology, 2011) or comparison of different services (Pilling, 2016).

Third, historical, sociological and discourse analyses would be helpful to elucidate the historical, political and linguistic forces which are contributing to the current reliance on guidelines and the dominance of 'evidence based practice' more generally (see e.g., Freshwater & Rolfe, 2004; Hall et. al, 2015)

Limitations

Consistent with its constructivist position, this study makes no claim that the findings are objective. The role of the researchers in co-constructing these data together with the participants is acknowledged, and different researchers may have co-constructed the analyses differently. As detailed in the methodology, numerous steps were taken to ensure transparency regarding the researchers' assumptions, beliefs and allegiances.

There were limitations to both recruitment approaches, with CPs known to the lead researcher it could be argued that pre-existing knowledge of the CP may have biassed sampling. CPs who responded to recruitment emails may have been motivated by particularly strong views for or against NICE guidelines. As the aim was to speak with typical CPs from routine practice, rather than those with particularly strong views, it was felt that a combination of both recruitment strategies would help offset the limitations of each approach. In an attempt to provide transparency, the decision making behind the selection of participants was documented in detail and is available in Court (2014b).

CONCLUSIONS

This study is the first to produce a theoretical framework which attempts to help explain why NICE guidelines are not consistently utilized in UK mental health services. The benefits of guidelines were valued; however, there were concerns about the harm that misuse of guidelines could do to service users and also to the profession of clinical psychology. The emergent theory challenges the assumption that there is a simple, linear relationship between knowledge and guideline usage. This study also highlights the importance of CPs finding ways to ensure that their particular skills are recognized and utilized in the current service and political context.

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"We could end up in a lot of trouble": teachers' communications with young children about mental health

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Abstract

Purpose – *Stigma towards people with mental health problems is a significant problem and appears trenchant despite recent anti-stigma campaigns. Attitudes develop in young children, and may be stronger and less malleable in adolescence. Early intervention may be important for mental health education and stigma prevention. Theory, evidence and practical considerations all suggest that teachers' involvement is key. By exploring communication about mental health between teachers and young children, it will be possible to elaborate how stigma develops and may be ameliorated. The purpose of this paper is to explore teachers' accounts of this communication and the factors that influence it.*

Design/methodology/approach – *Semi-structured interviews with 15 primary school teachers were transcribed and analysed using a grounded theory approach.*

Findings – *Discussions about mental health were largely absent from the classroom, due to teachers' anxiety. Teachers felt the need to protect children from exposure to people with mental health problems and even from information about the topic, believed they lacked the necessary expertise, worried that such discussions were outside their remit and were anxious about parents' reactions.*

Originality/value – *This was the first study to interview teachers on this topic and suggests that a significant opportunity to address fear and stigma is being missed. Teachers' silence may reinforce that mental health problems are taboo, and prevent children from developing knowledge and a language to talk about mental health. The inclusion of teachers in early mental health education and could promote better understanding and more inclusive attitudes, especially if supported by educational policy and curriculum.*

Keywords *Mental health education, Policy, Teachers, Grounded theory, School, Young children, Stigma prevention*

Paper type *Research paper*

1. Introduction

Prejudice, stigma and discrimination are significant problems for people who experience mental health problems. Their impact can be severe, including significant disadvantage with respect to income, employment and housing (Cooke, 2008; Thornicroft, 2006), as well as social exclusion lowered self-confidence and self-worth, and hopelessness (Baumann, 2007). For many people these problems cause more distress than the original difficulty (Cooke, 2008). Stigma also often leads to delays in help-seeking, with negative consequences for treatment outcomes (Pinto-Foltz and Logsdon, 2009). In recent years there has been significant government investment in anti-stigma campaigns aimed at the general public. Gains have been relatively modest and attitudes appear entrenched (Evans-Lacko *et al.*, 2014).

Stigmatising attitudes are commonly thought to develop in childhood through social influences including parents, siblings and children's media (Mueller *et al.*, 2014, 2015). Prejudice towards

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those with mental health problems (MHPs) is reported to develop from the ages of seven or eight (Hinshaw, 2005). This would suggest that primary school age may be the optimal point to intervene as derogatory attitudes are not yet fully developed or entrenched. Interventions directed at primary school children may be able to shape more positive attitudes towards mental health, thus preventing stigma before it develops.

Whilst there have been a number of projects delivering mental health education in schools and aimed at reducing stigma (see Schachter *et al.*, 2008; Yamaguchi *et al.*, 2011; Mueller *et al.*, 2015 for recent reviews and meta-analyses) only five were delivered in primary schools, and only one uncontrolled study was conducted in the UK (Shah, 2004). Within the UK primary school curriculum, the Social and Emotional Aspects of Learning programme aims to foster children's social, emotional and behavioural development. It has been viewed positively by staff (Hallam, 2009) but does not address MHPs directly. There have been recent calls for this to be changed (Siddique, 2015).

A second relevant factor is who delivers the teaching. Anti-stigma interventions in schools have most often been delivered by outside agents (e.g. Sholl *et al.*, 2010; Yamaguchi *et al.*, 2011). However, there are reasons to suggest that a more effective approach might be for interventions to be delivered by teachers, perhaps supported by others. First, teachers appear to have a significant influence on children's knowledge, attitudes and behaviours (Hess and Torney, 2009; Mueller *et al.*, 2015). Second, the fact that mental health is not currently part of the mainstream curriculum may itself send a message that it is a taboo subject. A recent petition to government to include mental health in the school curriculum achieved over 50,000 signatures (Syed, 2015). Third, some have argued (e.g. Pinfold *et al.*, 2003) that delivery by teachers would be a more normalising and inclusive approach than reliance on external agents, which may contribute to an impression that MHPs are unusual and only the domain of "experts". Fourth, incorporation in the curriculum and delivery by teachers promises to be a more robust and sustainable model than delivery by outside agencies whose funding arrangements are often insecure (see, e.g. Dearden, 2014).

However, some studies have found that teachers tend to be reticent regarding involvement in such interventions. Ventieri *et al.* (2011) found that some primary schools declined an invitation to participate in a teacher-led anti-stigma programme. Reasons cited included concerns about parents' reactions and about the appropriateness of teaching children about MHPs, together with a lack of confidence in knowing how best to respond to issues that might be raised. Askell-Williams *et al.* (2007) found that teachers felt that they lacked the necessary knowledge and confidence to implement a MHP module in secondary schools. Graham *et al.* (2011) used a survey to elicit the views of Australian primary and secondary teachers regarding mental health education. Most respondents felt they lacked the requisite knowledge, skills and confidence to deliver teaching on mental health. They requested more training, resources and parental involvement.

In order to plan effective mental health education initiatives, it is therefore necessary to understand the processes that might be influencing teachers' attitudes and beliefs about mental health, and the extent and nature of their current communication with pupils on this topic. To date, no studies appear to have examined this in detail.

The current study used a qualitative methodology, interviewing primary school teachers to elicit their views and to try to construct a preliminary theory of the processes that might be at play. It is hoped that the findings will inform not only further studies but also effective school-based interventions to address mental health related prejudice and stigma development, and will also influence curriculum and policy.

2. Method

2.1 Participants

Interviews were conducted with 15 practising primary school teachers from three schools, in London and Brighton. All had experience of teaching primary school children (i.e. ages 7-11). There were five teachers from each school, aged between 26 and 59 (mean age = 36.1) and with between 3 and 35 years teaching experience (mean teaching experience = 9.5 years). In total, 3 (20 per cent) were male, and 11 (73 per cent) were white British (one teacher identified as other white origin, one as black African, one as black Caribbean and one as mixed ethnicity). The schools were selected to be representative of the UK as a whole; ranging in size from small (158 pupils) to much larger than average (872 pupils), and from a majority white British to a majority ethnic minority population. The two London schools had higher than average proportions of children with English as a second language, and one school had a higher than average proportion of children with recognised special educational needs. All schools were rated of at least a "good" standard in recent national assessments.

2.2 Design

A qualitative design was employed using semi-structured interviews. These allowed the open-ended questions necessary to collect rich data. Topics covered included the extent and nature of teachers' current communication with pupils about mental health, the factors that affected this and ideas regarding how this topic might best be taught.

2.3 Procedure

Ethical approval for the study was obtained from Canterbury Christ Church University (Salomons) Research Ethics Committee. Headteachers at three primary schools in London and Brighton were contacted and agreed to distribute information about the study to their staff. Interviews were conducted at the schools by the second author, herself a former primary school teacher. They lasted 40-65 minutes and were audio recorded.

2.4 Analysis

Data were analysed using the grounded theory approach outlined by Charmaz (2006). This approach is widely used to examine subjective accounts regarding attitudes, beliefs and behaviours. Themes emerging from the data informed the development of a preliminary theoretical model, which was then reviewed against the transcripts in an iterative process. Guidelines for ensuring quality in qualitative research were followed (Williams and Morrow, 2009): initial and selected subsequent transcripts were independently coded by two researchers, regular audit meetings were held to discuss coding and the emerging theory, and respondent validation was obtained by sending participants a summary of the findings and eliciting comments. A reflective research diary was kept and bracketing interviews (Fischer, 2009) examined the possible role of the researchers' prior experience and beliefs on the analysis.

3. Results

The most striking finding was that discussions about MHPs appeared to be almost completely absent from the classroom. Figure 1 outlines a preliminary theory of some of the processes that appeared to underlie this absence.

This framework provides a possible way of understanding the absence of conversations about mental health in the classroom. Its three elements – teachers' emotions, teachers' beliefs and teachers' behaviours – will be described in turn.

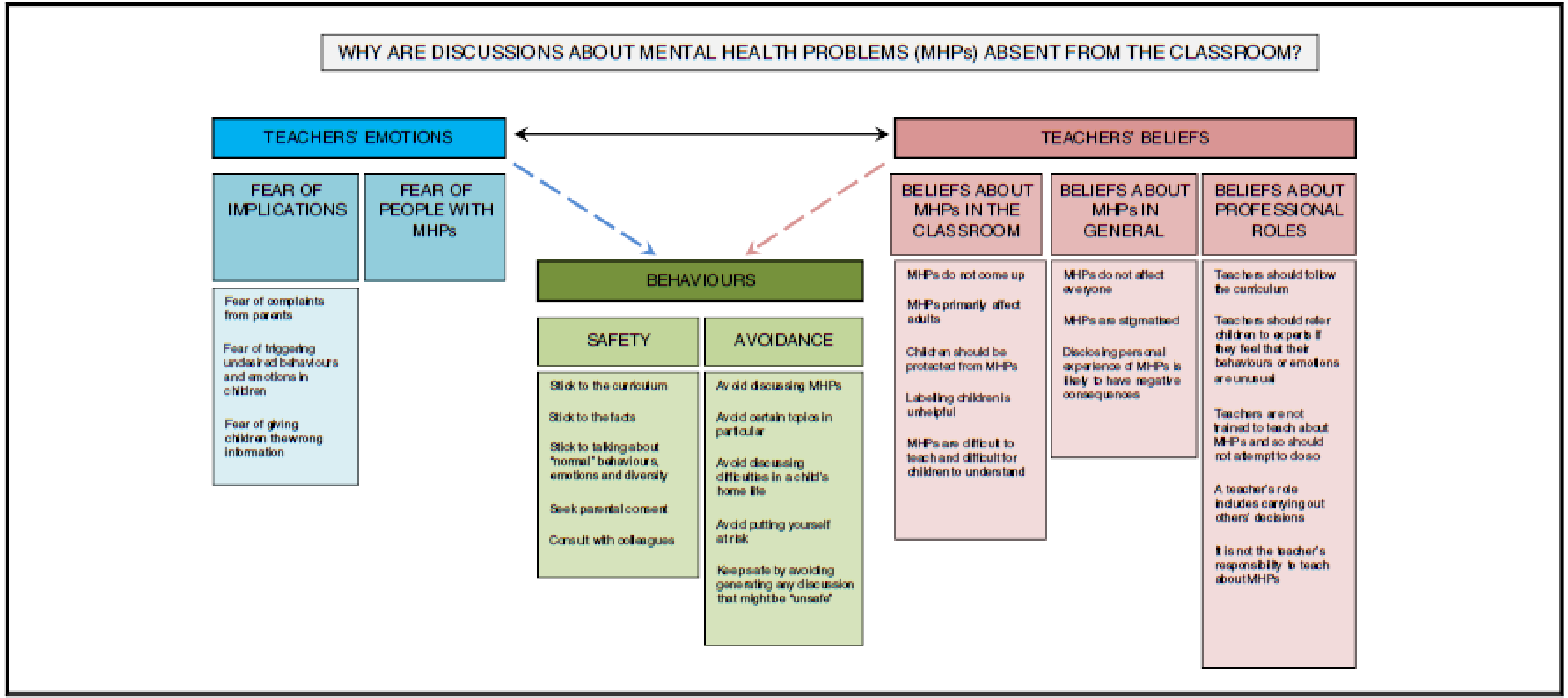
3.1 Teachers' emotions

The overriding emotion described by teachers was fear: fear of what might happen if they talked to children about MHPs, and fear of those who experience such problems.

3.1.1 Fear of complaints from parents. Teachers were concerned about how parents would react when they heard that MHPs had been discussed in the classroom, anticipating complaints:

> If a child goes home and says, "oh we heard about people today that get really depressed and sit in their room and shout and stuff", the parents get scared so they complain. You've got to worry about that now [...] about how parents react to stuff like that (Teacher H4).

Figure 1 Theoretical model accounting for why discussions of mental health problems are absent from primary school classrooms



3.1.2 Fear of triggering undesired behaviours and emotions in children. Teachers feared that discussing MHPs would result in children worrying that they had a particular problem or trying out undesirable behaviours:

> If you start to talk to some children about stuff like that […] it can almost encourage them to want to try it or to see how it feels (Teacher H4).

They were also concerned about upsetting children:

> Bringing it up […] they could feel upset, they don't know how to handle it […] I don't want to be the one to trigger anything in a child's life like that (Teacher X3).

3.1.3 Fear of giving children the wrong information. Teachers felt that they did not have the requisite knowledge and skills to talk to children about MHPs. They worried that discussions about MHPs might generate questions from children which they could not adequately answer:

> If I don't feel secure talking about something and I don't have a solid knowledge of it because if they ask me a question, I wouldn't want to give them an answer that wasn't accurate, or I wouldn't want to try to elaborate on something that I didn't know a lot about (Teacher X1).

Teachers often believed that expert knowledge was necessary for such discussions:

> They need to bring in an expert who will come and work with the children and myself […] I think that's safer for the children – I don't want to feel that I'm giving them the wrong impression […] some things I just think, I can't go any deeper because I just feel out of my depth and I'm worried that twenty years on children will turn round and say, "Mrs X told me that" (Teacher X4).

3.1.4 Fear of people with MHPs. Teachers were fearful of people with serious MHPs:

> You just see people that make you feel a little bit intimidated by their behaviour (Teacher L4).

They were also aware that wider society is also fearful, and cited media coverage associating such problems with violence as a factor in their avoidance the topic:

> The parents hear these terrible things on the news, "these psychotic killers have been released and gone and stabbed somebody", and they might think, "oh, you're going to tell my child that there's lots of psychotic people around" (Teacher H5).

3.2 Teachers' beliefs

In addition to fear, specific teacher beliefs also appeared to be playing a role: beliefs about mental health in schools, beliefs about mental health in general and beliefs about their professional role.

3.2.1 Beliefs about mental health in the classroom. Teachers held five main beliefs related to mental health in schools.

3.2.1.1 Mental health does not come up. Teachers frequently reported that mental health did not come up as a topic of discussion:

> It doesn't really come up as something they talk or enquire about so I suppose it doesn't open up the thoughts about having conversations about it (Teacher X5).

It is interesting to speculate what teachers meant in this regard: it seems likely that children had mentioned distressing thoughts or emotions, but teachers may have distinguished these from "mental illnesses" or "mental health problems" which they saw as something different.

3.2.1.2 MHPs primarily affect adults. Some teachers saw MHPs as more commonly affecting adults and so less relevant to children:

> With adults I associate it more with schizophrenia and things like that. OCD, paranoid disorders, things like that […] then with children, you never really hear of children with schizophrenia or OCD or anything like that (Teacher X1).

3.2.1.3 Children should be protected from MHPs. Some teachers suggested that primary school children were too young to learn about MHPs:

> I think you're just exposing them to something that maybe they don't need to know about yet (Teacher H4).

> I don't think they need to know that there's this thing called depression, there's this thing called OCD […] as an adult you like to know the names, the specifics, but as a child, because they're not in contact with it […] (Teacher X1).

3.2.1.4 Labelling children is unhelpful. Some teachers believed labelling should be avoided:

> What bothers me […] is the giving it a label […] it's like giving this child a label and we need to make allowances for them because they are X (Teacher L3).

3.2.1.5 MHPs are difficult to teach and difficult for children to understand. Mental health was thought to be a more difficult subject to teach and for children to understand than physical illness:

> I think because that's more abstract, because it's not physical and it's not visual, so it makes it more difficult to talk about, but it's also harder for them to understand (Teacher L3).

3.2.2 Beliefs about mental health in general. More general beliefs about MHPs also appeared to contribute to the absence of conversations about them in school. These included the idea that MHPs only affect certain people, that they are stigmatised and that disclosure is likely to have negative consequences.

3.2.2.1 MHPs do not affect everyone. Some teachers appeared to hold a binary view of MHPs as only affecting certain people:

> It's more normal, physical disability compared to mental disability. Something people think might affect them more (Teacher L5).

3.2.2.2 MHPs are stigmatised. Teachers appeared to see MHPs as stigmatised and discussion of them as taboo:

> I sometimes know if you mention that word "bipolar" it can be quite a taboo word whereas if you mention cancer, we had almost more sympathy for it but if you mention that she was bipolar people go, "oh she was mental then" (Teacher H5).

3.2.2.3 Disclosing personal experience of MHPs is likely to have negative consequences. Self-stigma was apparent, causing teachers to withhold communication about their own experiences of MHPs with their colleagues:

> You don't want to say because you're embarrassed and you don't want people to know, you don't want people to judge you (Teacher H3).

3.2.3 Beliefs about professional roles. Teachers' concerns about conforming to what was expected of them within their professional roles also contributed to the absence of conversations about mental health.

3.2.3.1 Teachers should follow the curriculum. Teachers stressed the need to stick to the national curriculum and that MHPs do not really feature:

> With everything else that's in the curriculum, if it doesn't come through the SEAL or PSHE (*Personal, Social and Health Education*) curriculum then it doesn't really get covered (Teacher X4).

Teachers felt comfortable talking about sensitive or emotional topics as long as they were part of the curriculum:

> It scares the hell out of them but they have to realise that people do die, so we have to teach the unit, and it is part of the curriculum (Teacher H4).

3.2.3.2 Teachers should refer children to experts if they feel that their behaviours or emotions are unusual. Teachers believed that their role was to notice "abnormal" behaviours or emotions and to refer on rather than becoming involved:

> But it's important that teachers sort of spot things […] because if we miss it that can turn into a major thing (Teacher X2).

> Occasionally you get children telling you something about their home life that's distressing, and I refer that usually to our designated person without really talking in too much depth with the child (Teacher L2).

3.2.3.3 Teachers are not trained to teach about MHPs and so should not attempt to do so. Teachers felt that they lacked sufficient knowledge or experience to talk to children about the subject:

> I've not actualy got the foundation to teach them about it. If I had relevant skills […] then I would do it but I would not go ahead and start bringing up an issue if I haven't got concrete evidence or ways to teach it (Teacher X3).

Teachers wanted training about MHPs, including knowledge about types of MHP and their causes. They also felt they needed guidance on what was appropriate to discuss with children:

> I don't think I'd feel comfortable with that […] I definitely would need to talk them through with somebody and have a consensus about what we could […] what's helpful to say (Teacher L4).

3.2.3.4 A teacher's role includes carrying out others' decisions. Teachers often felt that they had little freedom and that their role is to implement decisions taken by those further up the hierarchy:

> I just kind of follow orders and keep an eye on them […] but generally don't ask too much about it […] so yeah, just trying to keep back (Teacher X5).

When it came to managing situations regarding individual children, teachers were often guided by parents:

> You do get given a lot of guidance usually from family members, how to behave and what to say and what not to say basically (Teacher H4).

This suggests that teachers feel that it is outside their remit to communicate freely with children about MHPs or to decide what is communicated.

3.2.3.5 It is not teachers' responsibility to teach about MHPs. Some teachers thought that teaching children about MHPs was not within a teacher's role and that headteachers should bring in experts to deliver such teaching. Others felt that the responsibility lay with parents:

> I think that's with their family to support if they want their child to understand what it is […] (Teacher W1).

3.3 Teachers' behaviours

Teachers' fears and beliefs led them to act in particular ways, which within cognitive behavioural theory might be thought of as "avoidance behaviours" and "safety behaviours". Key here is that while such behaviours are understandable and often appropriate in the circumstances, they also prevent beliefs (e.g. that discussion of MHPs might upset children or provoke difficult questions) from being tested out (see, e.g. Clark, 1999).

3.3.1 Behaviours directed at safety

3.3.1.1 Stick to the curriculum. Teachers were wary of addressing sensitive topics unless they were on the curriculum:

> If it's in the national curriculum and they've suggested that you talk about it, then you do because you're covered I guess […] it's safer within the boundaries (Teacher H4).

Where a subject was incorporated in the curriculum, teachers believed that they would be covered by their unions should there be repercussions following classroom discussions:

> If you come away from that [curriculum] then you're not really covered if something happens from something you've said in class, or something that you have talked about, then you could end up in a lot of trouble, whereas if it's curriculum-based then I guess your union's there to cover you (Teacher H4).

This appears to lead to a situation where potentially sensitive topics not specifically part of the curriculum, notably including mental health, are not discussed, whilst other arguably equally sensitive issues such as death, alcoholism and homelessness are covered even when teachers are acutely aware of their impact, because they are part of the curriculum.

3.3.1.2 Stick to the facts. Teachers were worried about possible negative repercussions from opening up discussion of sensitive topics and so protected themselves by sticking to factual teaching:

> If you're just dealing with facts then it doesn't come back with "oh you're giving your opinion" or "saying this is that and it's not" and if I was just being scientific then I could say, "well they asked so I just gave them facts about" (Teacher X5).

With respect to MHPs, teachers reported feeling unsure of the facts and so avoided the subject.

3.3.1.3 Stick to talking about "normal" behaviours, emotions and diversity. Teachers made a distinction between MHPs and "normal" emotions and behaviours, and felt safer discussing the latter:

> We teach them how to deal with their anger and we teach them how to deal with certain situations (Teacher H5).

All participants felt safe giving children the message that everyone is different, diversity is to be celebrated, and everyone has equal rights:

> To send out the message that everyone is different and being different is a good thing [...] it's okay to be yourself and be different; be an individual (Teacher H1).

However, MHPs appeared not to be mentioned in these conversations.

3.3.1.4 Seek parental consent. Many teachers viewed education about mental health as analogous to sex education and felt that it would similarly require parental consent. It was viewed as a sensitive subject and teachers feared parental backlash:

> You'd have to involve parents in that kind of thing (Teacher L4).

3.3.1.5 Consult with colleagues. Talking with colleagues helped teachers to feel safer in their communication with children, having a shared sense of how to manage certain situations:

> With the knowledge of colleagues because, especially in education, you talk a lot to the other teachers (Teacher L5).

Teachers are influenced by their colleagues. If absence of discussion about MHPs is universal in classrooms, teachers are unlikely to have examples of helpful conversations about mental health to draw on, or to be able to access support in facilitating such conversations.

3.3.2 Avoidance. Teachers' beliefs and fears also led them actively to avoid certain types of conversations or encounters.

3.3.2.1 Avoid discussing MHPs. No interviewee described having such conversations:

> I've never discussed with them about mental health problems to be honest (Teacher L5).

Where one child had been identified as having a MHP, this was rarely if ever discussed with other children in the class:

> Children were kind of aware that he had, something was very wrong with his ability to control his anger, but I don't know if it was talked about really (Teacher L2).

3.3.2.2 Avoid certain topics in particular. There were commonly occurring topics that teachers were particularly wary of discussing: notably psychosis, schizophrenia and suicide:

> If a child says they're hearing voices in their head or something like that, I definitely wouldn't [try to discuss it] (Teacher X3).

> We've had like a few cases as well at our school of parents that have committed suicide as well, and it's kind of difficult because it did happen this year actually [...] we didn't really go into it with the other children because, you know, we didn't feel that that was really an appropriate thing to do (Teacher H1).

3.3.2.3 Avoid discussing difficulties in a child's home life. Talking about children's families was something most teachers avoided:

> I knew there were a lot of problems at home so you are talking around the problems at home because obviously you don't want to bring that up unless like [...] I think a lot of it was anger as well because of his home life situation so you tend to brush over that as well because you don't want them to bring that up (Teacher X1).

3.3.2.4 Avoid putting yourself at risk. Teachers chose not to communicate on subjects that felt in some way risky, including mental health:

> If you put yourself in a position where you are exposing them to something that possibly they don't want their child to be exposed to, then you're putting yourself in a position of risk, which you can't really do (Teacher H1).

3.3.2.5 Keep safe by avoiding generating any discussion that might be "unsafe". Teachers avoided opening up conversations about MHPs:

> You kind of skate over them, you don't get too deep, because maybe the age of the children and what other children will take from it, especially if it's not a planned kind of lesson (Teacher L2).

4. Discussion

This study examined how primary school teachers communicate, or do not communicate, with children about mental health. Its major finding was that – at least in the schools represented here – such communication appeared rare. Discussions of MHPs appeared to be largely absent from the classroom. This absence appeared to be related largely to anxiety on the part of teachers, leading to avoidance of the topic. Specific beliefs about MHPs, for example that they are abnormal and the domain of experts, also appeared to be playing a role as did specific beliefs about the role of a teacher to stick to the curriculum and to what they are specifically trained to teach. The idea that mental health is a taboo topic for teachers, and that teachers feel that they lack knowledge to discuss these issues, has also been echoed in secondary schools (e.g. Knightsmith, 2015; Knightsmith *et al.*, 2013). Interestingly many of these barriers are also found in parents' communications with children about mental health. Parents also felt anxiety and believed that such communication was for experts, and people with more knowledge than themselves, such as teachers (Mueller *et al.*, 2014).

In understanding the processes involved, the current social context appears important, both within schools and more widely. In particular, two factors may be relevant: on the one hand the current social narrative about mental health, and on the other the current political context of education.

4.1 The current social narrative about mental health

One factor that appears to drive teachers' fear is the current social narrative that people with MHPs are different to "normal" people, only understandable by experts and to be feared (Cooke and Kinderman, in press). This appears to be both a direct process (teachers share some of these beliefs) and an indirect one (teachers fear criticism from parents, and colleagues, for exposing children to this aspect of life). Ironically, a vicious circle may be at play whereby the dominance of this social narrative is one of the factors preventing interventions that could ameliorate it, such as effective mental health education in schools. Interestingly, interviews with parents have demonstrated that they do think that teachers have a role to play in teaching about mental illness, and they are more open to discussing it themselves, if they consider that mental illness may be experienced by "us" and "our" children (Mueller *et al.*, 2014).

4.2 The current political context of education

One notable feature of the interviews was the fear expressed by teachers: in particular, fear of criticism from parents and from managers. This may reflect the current political context of education where decision making regarding curriculum and teaching methods is increasingly centralised and teachers are required to conform and are subject to increased scrutiny and criticism (see, e.g. Benn and Downs, 2015).

4.3 Limitations and future research

There were a number of limitations to the current study. Most obviously, it was a small, qualitative study and its findings cannot necessarily be generalised. Social desirability may have played a role in the interviews: for example it is possible that some teachers did talk about mental health in the classroom but were hesitant to acknowledge it for fear of criticism. We are hopeful that the interviewer's (JK) previous experience as a teacher may have minimised this, although it remains possible that there were differences between reported and actual communication. Finally, although the themes were derived across all schools, there may have been differences in local institutional practices that were not explored in the current study.

The experiences, beliefs and commitments of the research team undoubtedly played a role in the analysis: for example they are all familiar with and value both cognitive behavioural and critical approaches to mental health. An obvious next step would be a larger-scale survey-based study, perhaps using questions generated from the current findings, exploring primary school teachers' classroom communications on this topic.

4.4 Possible ways forward

Despite their limitations the findings have a number of possible implications for future mental health education and anti-stigma interventions. First, it seems important to include mental health in the national curriculum for young children, and to include both teachers and parents in the implementation, perhaps through linked parents' nights. Second, teachers need training and support in order to deliver teaching on this issue. Recent Department for Education guidance goes some way to addressing issues of well-being, emotions and resilience (PSHE Association, 2015), but more work is needed to incorporate teaching specifically about mental illness. One possible model would be for people with particular expertise, including psychologists but also young people who have experienced MHPs, to support teachers, perhaps initially delivering teaching alongside them. A story-based intervention has recently been developed and piloted with this possibility in mind and with promising results in this age group (Greenwood *et al.*, in press). Third, a psychological, continuum-based approach, stressing that everyone experiences mental health problems to some degree or at some points, is likely to be a more effective approach in promoting accepting attitudes and preventing stigma than one based on the idea of discrete "mental illnesses" that only affect particular people (Cooke, 2003; Cooke and Harper, 2013; Read *et al.*, 2006; Mueller *et al.*, 2015). Materials are available to support such an approach and could be adapted both for teachers and for children (see, e.g. Basset *et al.*, 2007; Cooke, 2003, 2014; Cromby *et al.*, 2013; Kinderman, 2014; OnlyUs Campaign, 2015; Sholl *et al.*, 2010; Greenwood *et al.*, in press). Direct input from people with lived experience of MHPs will also be vital if future generations are really to understand that "There is no them and us. There is only us" (OnlyUs Campaign, 2015; Mueller *et al.*, 2014).

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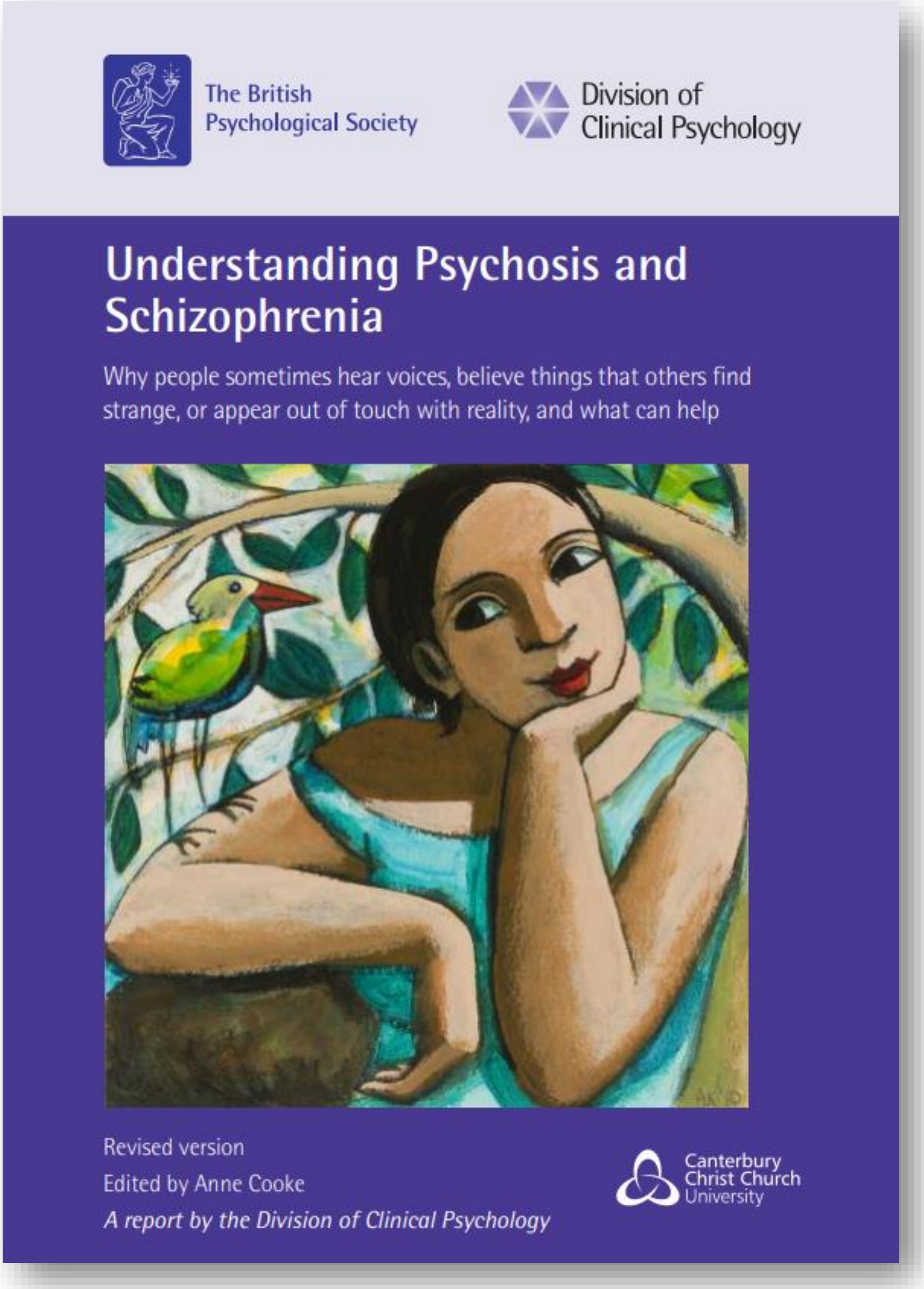
Understanding Psychosis and Schizophrenia

‘Understanding Psychosis and Schizophrenia’ is not included here as it is book length. It can be downloaded from https://cms.bps.org.uk/sites/default/files/2022-07/Understanding%20Psychosis%20and%20Schizophrenia.pdf or understandingpsychosis.net, and is available from online booksellers.



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Understanding Psychosis and Schizophrenia

Why people sometimes hear voices, believe things that others find strange, or appear out of touch with reality, and what can help

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Developing positive relationships with voices: A preliminary Grounded Theory

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Abstract

Background: Research has been exploring the phenomenon of 'voice hearing' within a relational framework. To date, studies have paid limited attention to voice hearers who view the experience positively.

Material: Semi-structured interviews were conducted with five mental health service users and seven non-service users who had had positive experiences of hearing voices. Interview transcripts were analyzed using Grounded Theory.

Conclusions: The preliminary theory suggests that the moderation of fear and control may impact on relationships with voices. Actively engaging with voices to understand their subjective meaning may be beneficial. Promoting a positive self-concept and connecting with communities who value and accept voice-hearing experiences may be particularly important.

Keywords

hearing voices, positive experiences, interpersonal relationships, community, stigma

Introduction

The experience of hearing voices that no one else can hear has traditionally been viewed as a sign of mental illness, such as schizophrenia or other psychotic disorders (American Psychiatric Association, 1994). However, it is now recognized that voice hearing is commonly reported within the general population (Romme and Escher, 1989; Tien, 1991; Van Os et al., 2000).

Accounts that ascribe positive meaning to the voice-hearing phenomenon have been documented across different cultural and spiritual groups throughout history (Al-Issa, 1977). Particularly in religious or shamanic practices, voices and visions are often seen as a gift and are encouraged and valued within the community (Prince, 1992). Voices in this context are often interpreted as spiritual messages, or connections with the divine, and provide inspiration, comfort and guidance (Watkins, 1998).

Although the majority of mental health service users report finding their voices distressing, researchers have found that a small number report neutral or even pleasant experiences (Judkins and Slade, 1981; Oulis et al., 1995), and some voice hearers report mixed reactions to their voices (Miller et al., 1993). A recent study found that 26% of a sample of 106 people diagnosed with schizophrenia or other psychoses reported pleasurable experiences associated with their voice hearing (Sanjuan et al., 2004). Although these studies present some quantitative data about the pleasurable aspects of hearing voices, the processes and factors that enable people to develop a positive understanding are not yet fully understood (Jones et al., 2003).

The role of a relational framework

Research has shown that hearers often describe their voices as having similar characteristics and attributes to real entities or people (Garrett and Silva, 2003; Nayani and David, 1996), and see the message or content of the voices as linked to a significant person in their life (Copolov et al., 2004). Benjamin (1989: 308) first reported that hearers seemed to have 'integrated, personally coherent relationships with their voice' and that these relationships seemed to be similar to relationships in the 'real' world. Subsequently, a number of studies have used interpersonal theories to investigate the voice-hearing experience within a relational framework (e.g. Birchwood et al., 2000, 2004; Hayward, 2003; Vaughan and Fowler, 2004).

Power and proximity

Researchers have examined the dynamic of power and control in the relationship between hearer and voice

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(Birchwood and Chadwick, 1997; Chadwick and Birchwood, 1994; Johns et al., 2002). Birchwood et al. (2000) investigated themes of power and rank and found that hearers who related to their voices from a position of subordination and powerlessness were more distressed irrespective of voice content. Furthermore, they found that the differences in perceived power and rank between hearer and voice appeared to mirror those in the hearer's social relationships, suggesting a causal role for interpersonal schema (Birchwood et al., 2004).

As well as issues of power and rank, some hearers also report experiences of companionship, trust and closeness in the relationship with the voice (Nayani and David, 1996; Romme and Escher, 2000). In order to build on the findings of Birchwood et al. (2000, 2004), recent studies have applied Birtchnell's (1996, 2002) Relating Theory to the voice-hearing experience. Relating Theory suggests that relationships can be characterized by two dimensions: power (strength and weakness) and proximity (distance and closeness). Vaughan and Fowler (2004) found that hearers who were distressed by their experience tended to perceive their voices as dominant and reacted by seeking distance. Hayward (2003) found that patterns of power (voice dominance and hearer submissiveness) and proximity (voice intrusiveness) in the relationship with the voice were significantly correlated with patterns of power and proximity in the hearer's social relationships.

Rationale for this study

Quantitative measures based on interpersonal theories may neglect important information about the relationship that hearers develop with their voices. Chin et al. (2009) explored some of these issues using a qualitative design and highlighted the importance of wider social contexts including culture, spirituality and stigma when exploring the relationship with the voice. However, their study focused on those who reported distress associated with voice hearing and did not explicitly seek to include people who had positive experiences.

Qualitative research that includes people who do not use mental health services may shed more light on how wider social issues may impact on the hearer's relationship to their voice with respect to power and proximity (Hayward, 2003).

Research questions

- How do people develop positive relationships with their voice(s)?
- What factors (internal and external) affect those relationships?
- How do these relationships change over time?

Methodology

Study design

The qualitative method of Grounded Theory was used as it was most suited to the aim of this study and is known as a useful methodology for researching the development and maintenance of complex and dynamic psycho-social processes (Charmaz, 2006; Patton, 1990; Willig, 2001). Particularly appropriate for an area which is under-researched, Grounded Theory aims to develop a model that is grounded in the experiences and contexts of the participants (Creswell, 1998).

Participants

Five men and seven women were recruited through local NHS services, community advertisement and the local branch of the Hearing Voices Network. All participants had positive experiences of hearing voices (or both positive and negative experiences), were over 16 years of age, fluent in English, and had heard voices for at least 12 months. Participants with and without a psychiatric diagnosis were included in the study. Participants' demographic information was obtained (Table 1) and all participants gave written informed consent before taking part in the study.

Data collection

Existing literature, service users' and psychologists' views and pilot interviews were used to inform the development of a semi-structured interview schedule (Smith, 1995; Willig, 2001). Participants were theoretically sampled, 'negative cases' were selected to ensure that areas of interest were examined closely, and emerging themes were validated (Charmaz, 2006; Willig, 2001).

Interviews lasted between 30 and 90 minutes and were conducted in a community mental health centre or local community centre. Each interview was audio-taped and transcribed for analysis.

Data analysis

Grounded Theory (Charmaz, 2006; Strauss and Corbin, 1998) was used to analyze the data. Data coding and analysis were conducted simultaneously to data collection, permitting themes to be investigated as the study evolved.

The computer software NVivo was used for managing and analyzing the data. Initial coding was conducted line by line and generated new ideas to pursue, leading to a second phase of coding. Focused coding was used to integrate and organize the data into preliminary categories. Axial coding was then used to investigate the properties and dimensions of the categories and to expand on the

Table 1. Participants' demographic information

Pseudonyms*	Gender	Age band	Ethnicity	Use of mental health services	Religious/ spiritual beliefs	Voice description
Ade	M	36–45	Black Nigerian	Yes	Shamanism	Heard voices since age 26. Heard the voice of his grandmother, his ancestors, the voice of nature, and an internal voice.
Sam	M	26–35	French/British	No	Spiritual	Heard voices since the age of 7. Heard the voice of imaginary friends, angels, higher self, dead relatives and spirit guides.
Mary	F	56–55	White British	No	Spiritual/ Scientology	Heard voices since childhood. Heard internal voice (higher self) and external voices (dead relatives, spirit guides/friends).
Lucy	F	26–35	White Zimbabwean	Yes	Spiritual	Heard voices for two years. Heard telepathic voices, guides, God, angels and the Devil.
Karen	F	36–45	White British	No	Spiritual	Heard voices since age 5. Heard spirit guides, telepathic voices and higher self.
Darren	M	36–45	White British	Yes	Born-again Christian	Heard voices since age 28/29. Heard spiritual voices, negative voices, telepathic voices and Christian God.
Audrey	F	46–55	White British	No	Greater power	Heard voices since childhood. Heard spirit guides and dead relatives.
Betty	F	56–65	White British	No	Spiritualist	Heard voices since childhood. Heard guides (beloved) and dead relatives/pets.
Kate	F	26–33	White British	Yes	Born-again Christian	Heard voices since age 9. Heard voice of God, the Holy Spirit and of Devil.
David	M	46–55	White Irish	No	Spiritual	Heard voices since childhood. Heard voice of grandmother, spirit guides and higher 'knowing'.
Tom	M	46–55	White British	No	Spiritual	Heard voices since age 25. Heard voice of guardian angel, grandparents and dead relatives.
Rachel	F	26–35	White British	Yes	None	Heard voices since childhood. Heard around 50 different voices (personalities).

* All names have been changed to protect participant confidentiality

emerging theory. Methods of constant comparison, memo writing, field notes and diagrams were also used to help in the generation of conceptual insights, and relationships and disparities in the data.

Quality assurance

In order to minimize researcher bias, sections of transcripts were analyzed and discussed with peers. The primary researcher (first author) was also reflexive throughout the process, writing a diary and discussing her experiences and biases during reflective interviews with a peer. Respondent validation was used to validate the research findings (Mays and Pope, 2000). This involved sharing the findings with two participants after the analysis was complete, in order to check that they considered their experiences to have been captured appropriately.

Results

This study set out to explore how people develop positive relationships with their voices and the factors that affect those relationships. A number of factors and processes emerged from the data analysis which appeared to be significant to the participants. A preliminary model of the development of positive relationships with voices was drawn up and summarized (Table 2).

Core processes

Two core processes seemed to develop over time:

- *Diminishing fear* seemed to be a central process in developing a positive relationship with the voice(s). Through diminishing fear (of the voice, the unknown, others' reactions and being mad) and embracing positive feelings (such as love and compassion for the voices, and acceptance of oneself) people were able to develop a greater understanding of and closer relationship with their voice(s).
- *Establishing control* was also central to being able to manage and develop a healthy relationship with voices. Developing an empowering understanding of voices helped to assert boundaries with the voice(s) and enabled the hearer to integrate the experience into his/her life.

Table 2. A preliminary model of the development of positive relationships with voices

Core processes	Diminishing fear Establishing control		
Categories that impact on core processes	Relating to voice and self	Connecting with a community	Developing a personally meaningful narrative
Subcategories	Personification of voices Actively engaging Asserting boundaries Developing a stronger sense of self and independence	Seeking understanding through others Developing a sense of belonging	Finding hope and 'ultimate meaning': Spirituality, culture and trauma Integrating and accepting voices: Creating balance

Three categories were identified as important factors that contributed to these core processes.

Relating to voice and self. *Personification of voices*. All participants experienced their various voices as being on a continuum of 'personification'. At one end the voices were experienced as lower beings (e.g. demonic energies) that were malevolent in intent and could not be trusted. In the middle of the continuum voices were experienced as 'ordinary beings' (e.g. sub-personalities or dead relatives) who, just like ordinary people, could have varying intent and could be more or less trustworthy. At the other end voices were experienced as 'divine beings' or a connection to a 'higher self' [Tom] (e.g. God, angels, spirit guides). Divine beings were experienced as having benevolent intent and could be trusted.

Participants reported close and trusting relationships with divine beings. They offered protection during difficult and traumatic times and were often called upon to help protect the hearer from more difficult voices and to assist in diminishing fear and establishing control. Divine beings were experienced as omniscient and omnipotent (e.g. knowing things about the person, predicting the future and warning of danger). However, most participants explained that they retained choice, independence and control:

> 'When you can't find a way out when you get into a complex situation, they help guide you. You don't have to listen, you don't have to take their advice but it's nice that they give it anyway.' [Karen]

Difficult or demanding voices (lower to ordinary beings on the continuum) were often compared to people in the hearer's social world:

> 'It's no different when you are out there and there is a bus queue and you will always get those who push in… who will trample over you.' [Betty]

Personification of voices developed over time and was shaped by the participant's understanding of and engagement with the voices:

> 'So I have learnt over the years that the one voice that I used to hear in my head, which was just a general voice, was actually one of my main, I call them inspirers rather than guides, you know, helpers, they help you.' [Mary]

Actively engaging. Actively engaging with the voices and dialoguing with them was helpful in increasing an understanding of the voices' purpose and reason for being, and contributed to personification. Actively engaging with the voice helped to eliminate fear and empower the hearer as the voices became known entities:

> 'Somehow in listening to the voices and dialoguing with them and figuring out who they are, the power balance shifts.' [Rachel]

Talking directly with the voices also increased trust and closeness within the voice relationship. If in trouble, many of the participants would actively ask more divine voices (e.g. God or spirit guide) for guidance and advice, which made them feel protected and comforted:

> 'You say "I'm having a bit of difficulty with this situation can you help me with it?".' [David]

Asserting boundaries. Being assertive and creating boundaries within the voice relationship helped the person to establish control and create a balance with everyday life. There were a number of ways that participants asserted boundaries including:

- Telling the voices to go away: 'Dismiss the negative voices tell them to go away, tell them to push off in Jesus's name. Don't give them any credence or attention.' [Kate]
- Protecting self with body-energetic and visualization techniques: 'But actually I know that while some things have tried to attack me, they haven't managed to because the boundary I have put around myself, which I call my heart energy, which if they try to get into it, they can't.' [Tom]
- Calling on divine entities for help and protection: 'I just say "go away, I'm not going to listen", and if

> they are persistent, especially if it is a [deceased] relative, I will just call my guide in, my inspirer in and ask "please can you ask them [deceased relative] to come back [later], because it is not appropriate". And they have to take notice of you.' [Mary]

Being able to assert boundaries was something that most participants said they had learnt over time:

> 'You have to learn that though. You have to learn that you have that ability to control.' [Mary]

People gained this knowledge through their experience with the voice and also through their connections with other hearers. Some people also saw their ability to assert boundaries as part of their intrinsic personality, or as arising from their independence and self-confidence.

Developing a stronger sense of self and independence. Having independence, 'choice and free will' [Tom] within the voice-hearing relationship was important in establishing control and diminishing fear:

> 'It's up to me. It's my choice. They are not ruling my life. I am ruling my life.' [David]

This inner strength empowered the hearer to assert him/herself in the voice relationship, and also with other people in their social world:

> 'I find it really hard if my own self-esteem is really low… If things are going well, then it is much easier to tell those voices to shut up or to challenge them, rather than to think what they are saying is true.' [Rachel]

Some participants described a process of self-development through the voice relationship itself, which made them stronger within themselves. This personal 'transformation' led to an increase in self-awareness and self-confidence:

> 'It has made me more sure of myself.' [Kate]

> 'It gave me confidence where I had been frightened before.' [Audrey]

Some participants described being encouraged by their voice, particularly when in difficult situations:

> 'Sometimes a voice will say "can you be more assertive than you are in this situation? Can you speak to such and such?'… But if you are standing up for yourself it's for everyone's benefit.' [David]

Connecting with a community. *Seeking understanding through others.* Most participants actively sought understanding and guidance from others (e.g. spiritual groups, church groups, the Hearing Voices Network):

> 'Obviously if you were somebody who was insecure and in fear you would think, "What is this?" It is an understanding… and that is why I guess I have been searching for the truth and the knowledge of what is going on with this and communicating with other like-minded people who also have psychic mediumistic abilities, because it helps us to understand who we are in this world.' [Karen]

Most participants felt that their voice-hearing experiences were meaningful and therefore sought alternative understandings (often spiritual) to an illness-based medical view. Those who had received a diagnosis of mental illness tended to view their voices as more than just 'a bunch of symptoms that need fixing' (Rachel). This often conflicted with the medical approach they were offered:

> 'They just wanted to put me on medication instead of dealing with why I was hearing the voices.' [Lucy]

> 'I don't go into detail about my religious beliefs in case they think it is part of my illness.' [Kate]

Therefore people sought connection with others who shared similar belief systems (e.g. the Christian Church).

Developing a sense of belonging. Participants spoke about the importance of connecting with 'like-minded people' [Karen]:

> 'I speak to those who are positive about spiritual life and positivity and positive entities. There are not very many of us about but it's just finding them.' [Darren]

Communicating with like-minded people seemed to develop a sense of belonging, as evidenced by the way participants talked about their experiences as a collective – 'People like us' [Karen]; 'I am part of these special people' [Ade] – and identifying with a group – 'as a born-again Christian' [Kate].

Most participants described having a meaningful role within their communities and social networks, which was linked to their voice-hearing experience. They exchanged experiences and coping techniques, and counselled and taught others. This gave them a sense of belonging and purpose and contributed to a change in identity which increased their self-esteem:

> 'You know, I wasn't this crazy kid, I had actually got something that I could use.' [Mary]

Gaining support for oneself and providing support for others increased participants' understanding of their own voice experience, which in turn reduced fear and increased a sense of control. Participants also gained hope from talking with others:

> 'I guess it was in talking to other people who were further on in that process already that made me aware what was possible.' [Rachel]

Developing a personally meaningful narrative. Finding understanding and 'ultimate meaning': Hope, spirituality, culture and trauma. All participants had personally meaningful and coherent understandings of their voices and had developed a personal narrative of their unique journey. The narratives provided a sense of hope and were meaningful to the person based on their own history (including past traumas), the beliefs they held and their cultural context.

These understandings developed across time and were influenced by a number of factors. First, most participants developed understanding directly through the relationship with their voices:

> 'It is a knowing. Because you feel it in your whole body, it is a knowing, it's who you are, it is an innate wisdom that we tap into and with that comes spirituality.' [Karen]

Understandings were also shaped through connecting with a community, and through other sources of information:

> 'They [voices] are showing me understanding. And so I have to go back and read my culture again to understand why is it?' [Ade]

In particular, participants who identified themselves as clairvoyant/mediums spoke to their clients who confirmed that their voice experiences were real. Positive feedback led hearers to develop an increased confidence in themselves, their beliefs and their voice experiences:

> 'Understanding what I can do has come through seeing faces of other people when you've actually got it right for them.' [Mary]

Eleven of the 12 participants had spiritual beliefs connected to their voice experience. People's spiritual beliefs and their relationship with their voices, particularly with divine beings, provided an increased sense of protection and control and eliminated fear through a process of surrendering and trusting:

> 'What I love about that is I overcame my fear of being me, of being alive and in this big world, and I don't feel alone in it. I feel supported in it by the universe in some ways, as though there is a safety net around me. It is this higher consciousness stuff that does that and knowing that, I feel indestructible. [Betty]

These feelings of 'ultimate meaning', inner knowing and connection to 'something bigger' [Karen] also acted to eliminate fear of other people's reactions to their voice experience:

> 'So it connects me to that kind of energy. They give to me in symbols. They communicate with me in nature. Nothing is alone. We are connected to everything. So for that I don't care if people say that I am mad or not.' [Ade]

One participant (Rachel) did not have a spiritual understanding of her voices. However, she talked about finding an alternative (to the biomedical perspective), trauma-based understanding of her voices through the Hearing Voices Network and through working with a private therapist. This understanding provided a different language to describe her experiences and also a sense of hope and meaning, which helped to provide a more positive view of the self, decreased fear and provided an increased sense of control:

> 'So understanding what was happening for me, giving it meaning and breaking down the fear that I had around not knowing and thinking that I was a complete freak, really different and ill.' [Rachel]

Integrating and accepting voices: Creating balance. All voice hearers seemed to have integrated their voices into their lives, and valued their contribution:

> 'They are very much a part of my life.' [Karen]

Even negative voices were seen as playing an important role in personal transformation and self-awareness. Finding a meaningful understanding helped the voices to become integrated into the hearer's life and helped to manage fear and led to feelings of acceptance:

> 'I'm much more comfortable with it all now and I just take it for… not for granted, but I just take it in my stride now.' [Sam]

Integration was closely linked with creating balance between the voice relationship and relationships and responsibilities in the 'real' world, as most hearers acknowledged that 'having your feet firmly on the ground is really important' [Tom]. Talking and socializing with people and doing normal 'everyday things' [Audrey] helped to keep the person in balance. Three participants also acknowledged that 'healthy scepticism' [Tom], and respectfully 'being challenged' [Betty] could also be helpful in this process.

Discussion

The preliminary model highlights the complexity of the processes involved in developing positive relationships with voices. Much of the research on voice hearing has shown that perceiving oneself to lack control within the voice relationship is an important factor in increasing distress (e.g. Johns et al., 2002; Nayani and David, 1996). The model suggests that having a sense of control and reducing the fear of voices helps the person to assert themselves and experience more choice and independence within the relationship. Furthermore, the model suggests that certain aspects of the voice relationship (e.g. gaining proximity to the voice through active engagement), connecting with other people who value and accept voices (e.g. gaining a sense of belonging), and developing a personally meaningful narrative of voices may help the person to develop a more positive relationship with their voice(s).

Clinical implications

Participants in this study were not typical of those who seek help from clinicians, as they experienced at least some of their voices as positive and over time had found helpful ways of understanding and managing them. Caution is therefore warranted when generalizing these findings to hearers who find the experience distressing. Nevertheless, here are some tentative suggestions for clinical practice.

Personification and active engagement. The model suggests that the process of personification may be helpful in developing a balanced relationship with the voice, thereby extending the findings of Chin et al. (2009) to people experiencing positive voices. This finding also supports suggestions from Leudar et al. (1997) that engaging and negotiating with voices may be associated with improved coping. More specifically, this study supports recently proposed interventions which work within a relational framework. These approaches aim to modify the relationship between hearer and voice by encouraging active engagement with voices in order to determine their intent and meaning, and negotiate new ways of relating to them. In particular, interventions that seek to engage voices and ‘get closer’ in order to establish control and diminish fear may be beneficial for some hearers (Davies et al., 1999; Hayward and May, 2007; Hayward et al., 2009).

Self-acceptance. Clinicians may also want to consider interventions that seek to enhance the person’s self-esteem and promote self-acceptance. Chadwick’s (2006) person-based approach uses techniques from cognitive therapy (e.g. role playing different aspects of the self) to help the hearer challenge negative self schemas and evidence a more flexible and positive view of the self. This approach has been found to be beneficial for people experiencing distressing voices (Goodliffe et al., in press). Narrative approaches (White, 1995; White and Epston, 1990) may also be considered. These aim to help the voice hearer to re-author their lives by constructing a more positive and coherent narrative about themselves and their voices which may lead to increased acceptance and integration. Chin et al. (2009) have also proposed that more emphasis should be placed on the strengths of the hearer, by using their existing coping strategies and promoting self-efficacy. This study suggests that working within the person’s own framework of understanding may be particularly important. This might be new to clinicians who have perhaps traditionally aimed to challenge those beliefs about voices (e.g. that they are those of spirits) that do not fit with the view that they are a symptom of mental illness.

Promoting community engagement

The aims of the above interventions appear similar to the helpful processes participants experienced through their various communities: greater engagement with and proximity to voices; exploration of meaning; acceptance of voices; and acceptance of self. For some hearers, the less-stigmatizing option of seeking alternative community and group support may be preferable and beneficial. Consistent with the requirement to practise in a socially inclusive manner (Department of Health, 2007), this suggests a possible role for practitioners as facilitators of engagement with voluntary, spiritual and community organizations which value and accept voice-hearing experiences. Practitioners might also want to consider establishing and facilitating self-help groups within the community which support hearers to come together to discuss their experiences and learn from each other (Meddings et al., 2006).

Limitations and future research

Most of the participants had a spiritual understanding of their voice-hearing experiences, arguably creating a bias in the sample. However, a wide range of belief systems were explored (e.g. born-again Christian, spiritualist, shamanic, paranormal) and the inclusion of a participant with a trauma-based understanding of voices showed that similar processes may take place regardless of spiritual beliefs. Further research could usefully include participants with positive experiences of voices who do not understand them within a spiritual framework.

This study raises questions about why some people choose to seek out various alternative communities and meanings, while others turn to mental health services for support. Both service users and non-service users who participated in this study spoke of the fear and stigma surrounding voice hearing. This appeared to encourage them to seek out alternative (non-NHS) support for their experiences, and in many respects this seemed advantageous. Further exploration of why some people seek alternative explanations while others seek help from mental health services may be important.

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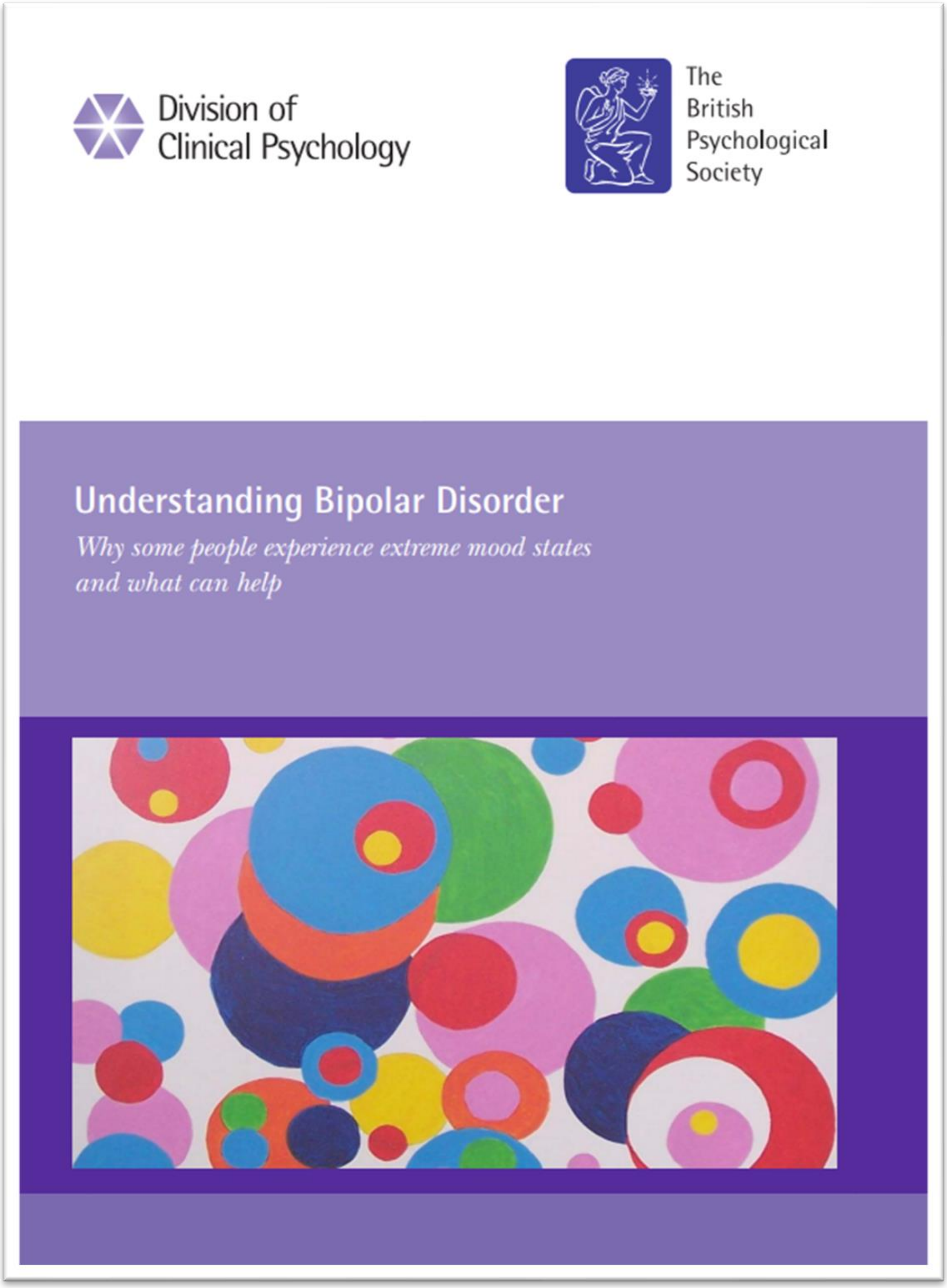
Understanding Bipolar Disorder is not included here as it is book length. It can be viewed at/downloaded from https://www.lancaster.ac.uk/media/lancaster-university/content-assets/documents/fhm/spectrum/understandingbipolar.pdf.



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Clinical Psychology

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Understanding Bipolar Disorder

Why some people experience extreme mood states
and what can help

◀ CHAPTER EIGHTEEN ▶

Problems associated with the use of the concept 'mental illness'

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> Depression is an illness with probable biological causes. (Eli Lilly, Prozac.com Web site, 2007)
>
> Schizophrenia is a devastating brain disorder. (Eli Lilly, Zyprexa.com Web site, 2007)
>
> The concept of schizophrenia is unscientific and has outlived any usefulness it may once have claimed. The label schizophrenia is extremely damaging to those to whom it is applied. (Campaign for the Abolition of the Schizophrenia Label, asylumonline.net, 2007)

Much writing about psychological distress, both in the specialist literature and in the general press, takes for granted the idea of 'mental illness'. There is often an assumption of underlying biological causation. As McCulloch *et al*. (2005) point out, however, this way of conceptualising certain types of behaviour and experience represents only one among a number of possible alternatives. The last two decades have seen a sustained and growing critique of the concept of 'mental illness' and associated terms. Some writers have concentrated on issues such as reliability and validity (e.g. Bentall, 1990) and others have pointed to political influence in the scientific process (e.g. Kutchins & Kirk, 1997). Others, however, have gone further to challenge the philosophical assumptions on which such classifications of human behaviour are based (e.g. Parker *et al*., 1995; Raskin & Lewandowski, 2000). Many of these critiques derive from broadly social

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constructionist or critical realist approaches to knowledge. Such approaches assume that the ways in which we view phenomena are at least in part a product of cultural and historical norms, and are heavily influenced by the power and status of the decision makers (Foucault, 1965). This means that the validity ascribed to different accounts of the world cannot be judged in purely objective or value-neutral terms.

Accordingly, a number of writers (e.g. Beresford, 2002; McCulloch *et al.*, 2005; Tew, 2002) have stressed the importance of moving beyond considerations of reliability and validity to examine the *utility* of the concept: its effects on those who use it, on those to whom it is applied and in society more generally; that is, its 'social, ethical and political consequences' (Harper, 2001, p. 21). This will form the focus of this chapter.

A number of potential positive effects have been suggested, the most common being that the concept of mental illness removes blame from the person affected (e.g. World Psychiatric Association, 2001). Other arguments commonly put forward include the role of diagnosis in providing reassurance that the person in question is not the only one affected, and that professionals know what is wrong and can help. Some writers have pointed to positive practical consequences such as decreased pressure to fulfil certain social role expectations (Perkins & Repper, 1998), material benefits such as housing and benefit payments (Campbell, 2007) and access to care and treatment. These arguments have been well rehearsed and will not be repeated here. Instead, the current review will focus on the potential negative effects of the concept that a number of authors (e.g. Gergen & McNamee, 2000; McCulloch *et al.*, 2005) have suggested comprise a neglected area. Some have linked this neglect to the vested interests and power of the mental health industry and, in particular, of pharmaceutical companies (e.g. Boyle, 2007).

As schizophrenia is arguably the prototypical 'mental illness' (see e.g. Thomas, 1997) it will form the major focus of this review. However, many of the arguments apply equally to other diagnoses as well as to related concepts such as 'mental disorder' and 'mental health problems'.

The first section of the chapter will examine the social meaning of the concept, which, it is argued, is distinct from professional conceptions, but germane to any evaluation of its effects. The second will examine its practical consequences, and the third its psychological effects on those to whom it is applied. The fourth will examine effects on professionals and on services. Finally, a number of possible ways forward will be suggested.

▶ Method for reviewing the literature

An electronic database search was carried out using the keywords 'mental illness', 'psychiatric diagnosis' and 'Diagnostic and Statistical Manual'. Publications referred to by database-identified authors were also consulted, together with a number of authored and edited books. Given the relative paucity of empirical studies in this area and the nature of the subject, it was considered important also to include conceptual critiques. The growing archive of writings emerging from the mental health service user and 'survivor' movement, documented by Rose (2001), was also consulted. Rose (2001) suggests that such writings have traditionally been excluded from the mainstream literature for reasons pertinent to the subject of this review:

> There is a growing archive of material . . . by people with first hand experience of mental distress and psychiatric services . . . The way users and survivors describe their experience is quite different to – indeed, sometimes at odds with – the descriptions we find in both the psychiatric and social science literature . . . But power is at stake because dominant discourses and practices will always try to undermine us by pathologisation and exclusion. (Rose, 2001, p. 1)

In an attempt to redress this imbalance and to give due weight to 'distinctive user voices' (Rose, 2001), the current review will draw extensively on this archive in the form not only of citations but also of direct quotations. It is hoped that inclusion of this material will also protect against the 'clinician's illusion' (Mordock, 1997: the fact that clinicians only tend to see those people who are most distressed by their experiences, and whose distress continues), which arguably skews the information available to many reviewers.

▶ The social meaning of mental illness

Many writers stress the fundamental impact not only of the 'official' meaning of being designated mentally ill (i.e. that contained in the official diagnostic manuals) but also of its social meaning. The term 'mental illness' and associated terms are part of ordinary language and carry cultural meanings. For example, 'schizophrenia' is often understood as signifying a 'split personality', unpredictability and violence (Read & Harré, 2001; World Psychiatric Association, 2001).

Professionals sometimes criticise the 'wrong' use of mental illness concepts by non-specialists and attempt to educate the public about their 'true' meaning (see for example the Royal College of Psychiatrists' leaflet on schizophrenia: RCP, 2007).

However, there is evidence that such 'lay beliefs' not only differ from those of professionals but are also resistant to change. Barker, Lavender & Morant (2001) found that both service users' and relatives' beliefs about the nature of the problem differed significantly from professional conceptions. Furnham and Rees (1988) examined lay beliefs about schizophrenia and found associations concerning dangerousness, amorality, egocentricity and a vagrant nature. Rogers and Pilgrim (1997) found that lay people viewed the word 'mental' in negative terms. These negative connotations appear to be increasing rather than decreasing over time: a survey commissioned by the UK government found that perceptions of mentally ill people as violent increased between 2003 and 2007 (Department of Health, 2007).

A number of writers have suggested that such negative associations may be inherent to the idea of 'mental illness'. Susko (1994), for example, suggests that the concept of a 'diseased mind' not only evokes disability, but also implies potential unpredictability or violence. Similarly, Hill and Bale (1981, p. 290) suggest that it 'makes the "mentally ill" seem just as alien . . . as the witches seemed to fifteenth century Europeans'. May (personal communication) suggests that the social meaning of 'schizophrenia' is so negative and deeply ingrained that it is unlikely to be possible to 'reclaim' the term in the same way that other devalued groups have reclaimed terms, for example 'queer'. Empirical evidence in support of such an analysis is presented by Read and Harré (2001), who found that biological beliefs about 'mental illness' were associated with increased rather than decreased stigma. They conclude that traditional anti-stigma campaigns, which promote the message that 'mental illness is an illness like any other', may do more harm than good.

Raskin and Lewandowski (2000, p. 32) point out that professionals are themselves not exempt from the effects of stereotypes and 'cannot . . . fully detach themselves from their own internalised social constructions about the meanings of those labels'.

Activity 18.1

- What are your beliefs about mental illness?
- Where did you get those beliefs from?
- What experiences have informed those beliefs?

Finally, a number of writers (e.g. Deegan, 1993; Hayward & Bright, 1997) note that that such internalised social constructions also have a significant impact on those who themselves receive mental illness diagnoses. This is discussed in more detail below.

▶ Practical consequences of the concept of mental illness for those so diagnosed

Chamberlin (2001, p. 7) highlights the discrimination and disadvantage faced by those designated 'mentally ill':

> Stigma will not be overcome by public relations campaigns . . . Discrimination against labelled people is real: (. . .) laws that provide for involuntary treatment, practices restricting employment opportunities and the like.

The various forms taken by this discrimination and disadvantage are examined in the following section, together with evidence that the concept of 'illness' is a significant contributing factor.

Avoidance

Martin, Pescoslido and Tuch (2000) conducted a large-scale study and found that respondents who labelled the behaviour described in a vignette as 'mental illness' also expressed a wish for greater social distance.

Harsh treatment

Mehta and Farina (1997) found that participants increased the intensity and duration of 'electric shocks' more quickly if they understood their experimental partner's problems in disease terms than if they believed that they were a result of childhood events. The authors suggest three possible reasons for this: that viewing distressed people as sick produces a patronising attitude in which they 'like children, must be treated firmly' (Mehta & Farina, 1997, p. 416); that a belief in biochemical aberrations renders those affected 'almost another species'; and that that the idea of (random) 'illness' makes people feel vulnerable.

Unemployment and financial disadvantage

Unemployment rates are extremely high in those diagnosed with mental illness (Sayce, 2000). There is evidence that this is often due to prejudice rather than impairment. Rothaus *et al.* (1963) found that 'patients' who presented to potential employers explaining their problems in terms of mental illness were evaluated less favourably than 'patients' explaining similar problems in terms of relationship difficulties. Link (1982) found that people with a 'mental illness' diagnosis were disadvantaged in terms of both income and work status relative to individuals with similar difficulties, but who had not received a diagnosis. Farina and Felner (1973) found that employers were less likely to offer positions to those with a mental illness diagnosis, even where other variables were controlled for. Some professions exclude applicants with certain psychiatric diagnoses: critics have suggested that such policies are based largely on prejudice (Perkins & Repper, 1998). Similarly, many insurance companies refuse life insurance to anyone with a 'mental illness' diagnosis (Dunn, 1999).

Denial of rights accorded to others

Freedland (1998, p. 4) points out:

> One group in the country has fewer rights than the rest of us . . . some can't even vote. They can be discriminated against at work and locked up even when they have committed no crime . . . now the Government is set to erode their liberty yet further. They are the mentally ill.

The British Psychological Society (2001) has pointed out that the existence of separate 'mental health' legislation targeted only at those deemed 'mentally ill' is inherently discriminatory: together with terrorists, those labelled mentally ill are the only group who can be detained without trial. It has suggested that a better way forward would to have laws dealing with capacity on the one hand (the ability to make relevant decisions) and dangerousness on the other. People with 'mental illness' diagnoses are also excluded from doing jury service and in some circumstances from driving (Dunn, 1999).

Activity 18.2

Think of a time when you were excluded from something for whatever reason. How did you feel?
Imagine what it would be like to have those kinds of feelings every day.

▶ Psychological effects of the concept of mental illness on those so diagnosed

A number of writers suggest that in addition to the 'real-world' effects, the concept of mental illness has important psychological effects on those so diagnosed.

Hopelessness and decreased confidence

An effect described by many is the hopelessness and lowered confidence that can often follow a diagnosis of mental illness (e.g. Sellar, 2000). Many of these authors conclude that that this is often a consequence of the label itself rather than the original problems.

A number of writers have suggested that this can lead to a vicious cycle of hopelessness and lack of confidence leading to withdrawal. Raskin and Lewandowski (2000, p. 17) quote a service user who avoided job interviews despite being employable, stating 'I can't hold down a job . . . I'm a schizophrenic'. There is evidence that outcome is worse for those who accept the label of 'mentally ill' than for those who reject that identity (Susko, 1994). May (2000a, p. 15) suggests that accepting the diagnosis of schizophrenia that he received would have led to a 'long-term career as a psychiatric patient'. Similarly, Campbell (1996, p. 57) writes:

> the idea of illness . . . is not a dynamic, liberating force . . . While we harbour thoughts of emotional distress as some kind of deadly plague, it is not unrealistic to expect that many so-called victims will lead limited, powerless and unfulfilling lives.

The social role of 'mental patient'

Several writers note that the concept of mental illness is closely associated with the social role of 'mental patient', which for many comes to dictate their primary identity: 'They are enjoined to become community mental patients, live an extremely restricted life and be socially excluded from mainstream society' (Rose, 2001, p. 2). Deegan (1993, p. 7), for example, describes her reaction to receiving the diagnosis:

> I was told I had a disease . . . I was beginning to undergo that radically dehumanising and devaluing transformation . . . from being Pat Deegan to being 'a schizophrenic'.

Some writers describe the 'perverse incentives' that can operate when the 'illness' role becomes someone's only source of power. Coleman (1999, pp. 160–61), for example, writes:

> In 1993 I gave up being a schizophrenic . . . not an easy thing to do, for it means taking back responsibility for yourself, it means that you can no longer blame your illness for your actions . . . Many of us think that our only power is this so called illness.

These concerns have been echoed in the professional literature. The best-known example is perhaps 'labelling theory' (Scheff, 1966), which recently appears to be attracting increased attention (e.g. Hannigan, 1999).

Decreased ownership and agency

A number of writers suggest that viewing one's experiences as symptoms of mental illness can lead to a reduced sense of ownership of the experiences and a decreased sense of agency in developing 'strategies for living' (Faulkner & Layzell, 2000).

Pilgrim (2000) suggests that while 'mental illness' terms may serve a function for professionals in marking what they consider their 'territory' and constructing them as experts, the mystique that they create is unhelpful and disempowering for others, including service users. A number of writers (e.g. Barham & Hayward, 1991) have suggested that this 'colonisation' by professionals risks militating against a sense of agency for those affected, and brings with it an implication that the only thing to be done is passively to comply with treatment, rather than mobilising one's own resources and coping abilities. Pembroke (1996, p. 34) describes such an experience:

> By giving up ownership of my experiences and the right to self-determination I was allowing my self-respect to be stolen from me. Ownership had gone to the blue file in the filing cabinet.

A number of empirical studies have reached similar conclusions. Birchwood *et al.* (1993), for example, found that people who accepted their diagnosis reported lower perceived control over illness. Fisher and Farina (1979) found that presenting a social learning explanation of their distress to clients led to more efforts to change than presenting a disease explanation.

Denial of the meaning of experiences and their possible relationship to the person's environment

A related point made by a number of authors is that to see experiences as merely indicative of 'illness' is to deny their subjective meaning, relationship to the person's history and environment, and possible function. May (2001), for example, describes his admission to hospital:

> Crucial in the next few months was that decision to . . . dismiss everything I was going through as a kind of a meaningless product of a carnivorous illness, a disease called schizophrenia, which I think is a very contentious idea. There's a lot of evidence to suggest that people's psychotic experiences . . . are actually responses to their environment [and] have an emotional meaning to them.

Of relevance here is the concept of 'insight', criticised by a number of writers as equating with agreeing with professionals, definitions of which often involve accepting that that one's experiences are meaningless symptoms of an illness (British Psychological Society Division of Clinical Psychology, 2000; Harper, 1999; Perkins & Repper, 1998). Some definitions of insight even include 'compliance' (e.g. David, 1990). The concept has also been widely challenged in the service user/survivor literature. Rose (2001), for example, suggests that dismissing service users' frames of reference as 'lacking insight' can be a means by which professionals exercise power. Campbell (1996, p. 57) writes that 'the concept of insight . . . lack of insight . . . is one of the most powerful and insidious forces eroding our position as competent, creative individuals'.

Other writers have suggested that psychiatric conceptions of insight are opposite to psychodynamic definitions, which often involve an acceptance that 'symptoms' have a meaning that needs to be explored and may be related to the person's history (Beck-Sander, 1998). With the exception of some psychoanalytic writers and of course the 'antipsychiatrists' (e.g. Laing, 1965; Szasz, 1961, 1979), however, until recently few writers in the professional literature had challenged disease explanations of 'psychotic' experiences. Nevertheless, in the psychological literature at least, a consensus now seems to be emerging that 'psychotic symptoms' can have meaning and function, for example playing a role in the emotional processing of traumatic experiences (e.g. Morrison, Frame & Larkin, 2003). In common with perhaps the majority of those writing from personal experience (e.g. Campbell, 2007; Coleman, 1999; May, 2000a, 2000b; Pembroke, 1996), many of these writers reject the concept of 'mental illness'.

Denial of the positive aspects of experience

A number of writers in the service user/survivor literature point out that there are positive as well as negative aspects to their experience, and many feel that these are denied by dismissing those experiences as 'illness'. Perkins (1999), for example, prefers the concept of disability to that of illness because of the implication that 'ill' people are unable to function. She writes:

> My manic depression is responsible for a great deal of the positive energy in my life. For a great deal of the time I am blessed with buckets of energy . . . My thoughts work like liquid crystal . . . I feel extremely engaged with, and part of, life. (Perkins, 1999, p. 137)

Similarly, O'Hagan (1993, p. 17) writes, 'How different my mood swings would have been if they were judged to be a talent rather than an illness'.

One of the stated aims of the organisation Mad Pride is to highlight and celebrate the positive aspects of 'madness', a term it is careful to distinguish from 'mental illness' (see www.ctono.freeserve.co.uk/mpname.htm). It has published an anthology of 'accounts of personal empowerment and liberation through madness' (Curtis *et al.*, 2000). An annual 'Bonkersfest' now takes place in South London. The Web site (www.bonkersfest.com) describes it as 'a free annual one day summer arts and music festival, illuminating creativity, madness, individuality and eccentricity' and claims to have 'identified normality as a mental health issue'.

May (personal communication) points out that pride and celebration can be selective:

> Mad Pride is about selectively valuing and celebrating the positive aspects of madness as perceived by the individual. For example . . . I am able to celebrate . . . creative aspects of my psychosis and see it as the initiation of a healing process.

Activity 18.3

Think of a time when you felt stereotyped or labelled.

- How did you feel?
- How did you cope?
- What did you do?

Effects on professionals and services

In addition to the social and psychological effects on the individuals so labelled, the concept of mental illness appears to have far-reaching effects on services for psychological distress and on those who work in them.

A misleading impression of certainty

Coppock and Hopton (2000) suggest that one frequent consequence is the process of reification, whereby clinicians come to think in terms of real entities such as 'depression' or 'schizophrenia'. This can lead to circular reasoning in which the symptoms are seen as being caused by the 'disorder' (Pilgrim & Hewitt, 2001). There is evidence that clinicians often believe in the inevitability of a chronic, deteriorating course for 'schizophrenia' that, although not supported by evidence, can lead to hopelessness and therapeutic pessimism, which have adverse impacts on service users (Accoroni, 2000; Sellar, 2000). Barrett (1988) suggests that this belief also frames which symptoms are noted and reinforced, and how someone's history is interpreted, culminating in a characterisation of the person's life as 'an epic of failures' (Barrett, 1988, p. 93).

Promotion of 'them-and-us' thinking

Harper (2001) suggests that the idea of 'mental illness' set up the assumption that that those with mental health problems are 'Other'; that is, separate and different from 'Us' who are normal. This 'them-and-us thinking' is perhaps particularly evident in mental health services (Harper, 2001; May, 2000b). While it arguably fulfils a defensive function for staff (Hinshelwood, 1998; Menzies, 1959), many authors (e.g. Onyett, 1998) present evidence that its overall effect is to reduce job satisfaction and increase burnout, and that effects on service users are overwhelmingly negative. This view is echoed throughout the service user/survivor literature (e.g. Campbell, 2007; Coleman, 1999; Deegan, 1993).

A narrow conception of people's difficulties and of possibilities for change

White (1995) suggests that mental illness concepts offer 'thin descriptions': superficial ways of viewing phenomena, devoid of the richness of real life. A number of authors (e.g. Johnstone, 2000; Pilgrim, 2000) argue that the use of such concepts can lead workers to adopt an impoverished, reductionist view of their clients' difficulties, and can distort their focus of attention, for example directing attention away from aspects of people's problems that do not fit the label. Harper (2001) points out that this can lead workers to stop being curious about individual clients, seeing them as yet another example of 'anxiety' or 'schizophrenia', and assuming that we know in advance what they will find helpful. A number of writers in the service user/survivor literature (e.g. Campbell, 2007) describe the sense of alienation that can result.

Overemphasis on individual differences and individualised approaches to change

A number of writers have pointed out that to conceptualise a problem as 'mental illness' is to locate the problem within the individual rather than within their social context or even in the 'fit' between the two (e.g. May, 2007; Pilgrim, 2000). Some (e.g. Harper, n. d.) have characterised this as 'victim-blaming', and suggested that one effect of this has been the channelling of resources into services that attempt to change individuals at the expense of those that target social conditions. Approaches directed at the latter, such as community psychology projects (e.g. Holland, 1992) do exist, but in much smaller numbers than individual 'treatment'-based services.

Narrow conceptions of 'treatment' and 'treatment effectiveness'

A number of authors have argued that the idea of illness has led to an overemphasis on 'technical fix' approaches to distress such as medication or technique-based therapies, at the expense of broader, relationship-based approaches (Barker, Lavender & Morant, 2001; Deegan, 1993; Onyett, 2000; Pembroke, 1996).

Raskin and Lewandowski (2000) argue that the concept of mental illness advantages approaches that value symptom reduction over personal meaning. Similarly, Birchwood (personal communication) points out that treatment trials generally measure – and value – reductions in 'symptoms' (e.g. voices) rather than reductions in distress, increased life satisfaction or other variables considered relevant by the person concerned.

'Evidence-based practice' generally relies on studies and reviews that use diagnostic categories. Some of these (e.g. Roth & Fonagy, 1996) acknowledge that this is problematic, but usually claim that there are few alternatives. As services in the UK become more protocol driven, the power of diagnoses in determining the service someone receives is likely to increase.

Seligman and Peterson (2003) suggests that psychologists should resist this development:

> The search for empirically validated therapies has in its present form handcuffed us by focusing only on validating the specific techniques that repair damage and that map uniquely into DSM-4 categories . . . By embracing the disease model of psychotherapy, we have lost our birthright as psychologists.

Narrowing the focus of research

Pilgrim (2000) points out that current service provision is planned on the basis of 'psychiatric epidemiology'; that is, the numbers of diagnoses given rather than estimates of need, vulnerability or risk. More generally, most mental health research is based on an assumption of 'underlying illness' and categorises participants by diagnosis (Boyle, 1999). The vast majority is funded by drug companies (Coppock & Hopton, 2000). It is obviously in these companies' interests for a wide range of experiences and behaviours to be interpreted as symptoms of mental illnesses. Indeed, there is evidence that new diagnostic categories are enthusiastically promoted by drug companies because of the associated opportunity to renew patents on existing drugs (Johnstone, 2000). Moreover, even statutory and charitable agencies usually require the use of diagnostic groupings in research (Bohart, O'Hara & Leitner, 1998).

▶ Conclusion and possible ways forward

In conclusion, it appears that there are a number of problems associated with the concept of mental illness. This review has not attempted to compare these against the opposing arguments in order to arrive at a judgement. However, in order to inform future debate about this issue, it seems appropriate to end with a consideration of possible alternatives. A number have been put forward: space only permits a brief mention of some of these. They divide approximately into possible ways of *describing experiences* on the one hand and possible approaches to *offering help* on the other.

Alternative approaches to describing experiences and problems

Mary Boyle (1999, 2007) contrasts diagnosis with what she calls a 'descriptive' approach. Such an approach starts from the premise that we are not justified in ignoring any aspects of behaviour, experience or distress and that we must make as few inferences about them as possible. This means trying to account for what people do and what they say they experience, rather than for a hypothesised illness. Boyle also stresses the need to take into account the effects of the person's situation, and to acknowledge that people actively interpret their experiences.

A number of writers suggest drawing on people's own ways of describing and understanding their experiences (e.g. May, 2007; Read, 2001; Rose 2001), and stress the importance of working within the person's own frame of reference rather than imposing the worker's. Such an approach contrasts with the traditional 'expert' model where the role of the professional is seen as explaining to the client the 'true' nature of his or her experiences (Hulme, 1999). A number of popular self-help movements, notably the Hearing Voices Network (de Valda, 2001), are explicitly based on the principle that different explanations exist and are helpful for different people. This approach appears gradually to be gaining acceptance in the more mainstream literature. A report by the British Psychological Society Division of Clinical Psychology (2000), for example, states:

> Professionals and other mental health workers should not insist that all service users accept any one particular framework of understanding. This means, for example, that professionals should not insist that people agree with their view that experiences such as hearing voices and holding unusual beliefs are always symptoms of an 'underlying illness' such as schizophrenia. Some people will find this a useful way of thinking about their difficulties and others will not. (British Psychological Society Division of Clinical Psychology, 2000, p. 59)

Others (e.g. Perkins & Repper, 1998; Sayce, 2000) advocate a 'social disability' model that stresses the role of the social environment in determining the extent to which certain experiences (e.g. fluctuations in mood) prevent people from fulfilling desires and social roles (e.g. working). Such approaches incorporate certain aspects of more traditional approaches to 'psychiatric rehabilitation' (e.g. Wing, 1978).

Alternative approaches to offering help

A number of writers have suggested possible ways of offering help that do not draw on traditional notions of illness and treatment. Many of these arise directly from the approaches to describing experiences outlined above, and all stress the idea of collaboration.

Many stress the need for a 'holistic' or 'whole person' approach, which does not attempt to treat 'symptoms' in isolation from the rest of the person's life (e.g. British Psychological Society Division of Clinical Psychology, 2000; May, 2004). Others emphasise possibilities for self-help (e.g. Read, 2001), for recovery independent of 'treatment' (e.g. Deegan, 1993), or suggest focusing efforts on changing the environment rather than the person (e.g. Joseph, 2007; Perkins & Repper, 1998). A number of writers emphasise the importance of attending to people's own narratives about their experiences, and helping them to develop these (e.g. Barker, Lavender & Morant, 2001; May, 2007; Susko, 1994; White, 1987, 1995). Others suggest the need to study 'resilience' and the strategies that enable some people to cope with even quite severe difficulties or unusual experiences without ever coming to the attention of services (e.g. Harper, 2001; Romme & Escher, 1993). An increasing number of authors (e.g. Joseph, 2007; Social Perspectives Network, www.spn.org.uk) are drawing attention to the social origins of distress and calling for a 'public health' approach that focuses on changing social conditions (such as unemployment, poverty and poor housing) that are known to be associated with increased psychological distress.

With respect to more traditional psychology and psychotherapy services, there are calls to resist managed care initiatives and protocol-driven treatments (Holmes, Newnes & Dunn, 2001) and to eschew the 'expert' model of help in favour of 'collaborative conversation' (Hulme, 1999). Many authors stress the central importance of relationships rather than techniques, and draw attention to the potential damaging effects of compulsion in mental health services (e.g. Onyett, 2000).

An apt conclusion is perhaps provided by Wallcraft and Michaelson (2001, p. 185):

> It may be that the fundamental changes in law and service provision . . . will only happen once popular notions of mental illness belonging to the discourse of psychopathology formulated in the 19th century have been transformed by the social action of the self advocacy movement and its allies.

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Identifying potential predictors of traumatic reactions to psychotic episodes

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Objectives. The experience of a psychotic episode can sometimes lead to post-traumatic stress disorder (PTSD) symptoms. The objective of the research was to identify candidate predictors of such negative reactions for future prospective study. We examined six predictors identified from the PTSD and psychosis literatures in a retrospective study: a history of previous trauma, a history of previous episodes of psychosis, perceived helplessness and uncontrollability at the time of the index psychotic episode, the content of persecutory delusions at episode and the perceived presence of crisis support after the psychotic episode.
Design. The design was a cross-sectional self-report and interview study of people with recently remitted symptoms of psychosis.
Method. 36 individuals with delusions and hallucinations that had remitted in the past year were assessed for the presence of PTSD symptoms in reaction to their most recent psychotic episode. Measures of the potential predictors were also taken at this point and associations with PTSD symptoms tested.
Results. 61% of the individuals with remitted positive symptoms had a reaction to their psychotic episode that was potentially severe enough to receive a PTSD diagnosis. Higher levels of PTSD symptoms were associated with all six predictors tested.
Conclusions. The study provides further evidence that negative reactions to psychotic episodes are relatively common. Clinicians may wish to assess for such symptoms. The study extended these findings by identifying a number of candidate psychological predictors of PTSD reactions such as perceptions of uncontrollability and absence of support. Prospective longitudinal studies are required to test the causal significance of these factors. More broadly, the findings indicate that traumatic stress in response to intra-psychic events such as delusions can be understood in similar ways to traumatic stress arising from physical traumas such as disasters.

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Psychotic episodes can be adverse experiences. Most obviously, the positive symptoms of psychosis can be distressing. For instance, individuals may believe that they are to come to terrible harm or that they have been taken over by evil spirits. It has also been suggested that contributing to traumatic stress may be: aspects of treatment such as being involuntarily admitted (Morrison, Bowe, Larkin, & Nothard, 1999; Priebe, Broker, & Gunkel, 1998), the shattering of previously held assumptions about the self (Jeffries, 1977) and threats to resources such as the ability to work (Bayley, 1996). Therefore, there are several aspects of a psychotic episode that could plausibly be perceived by patients as threatening and elicit fear, helplessness or horror. Increasingly, it is being recognized that a psychotic episode can be perceived as a potentially traumatising event that can lead to symptoms of post-traumatic stress disorder (PTSD; e.g. Lundy, 1992; Morrison, Frame, & Larkin, 2003). This is also consistent with recent evidence that life events can generate as many PTSD symptoms as traumatic events (Mol *et al.*, 2005).

A number of studies provide evidence that PTSD in response to psychotic episodes can occur (Frame & Morrison, 2001; McGorry *et al.*, 1991; Meyer, Taiminen, Vuori, Aijala, & Helenius, 1999; Shaw, McFarlane, & Bookless, 1997; Shaw, McFarlane, Bookless, & Air, 2002). The studies, with differing methodologies, find markedly different rates of post-psychotic PTSD (P-PTSD) ranging from 11% (Meyer *et al.*, 1999) to 67% (Frame & Morrison, 2001). The prevalence rates are likely to differ depending upon the selection of study participants, the assessment methods, and the length of follow-up. Nevertheless, the indications are that P-PTSD is a co-morbid problem for some individuals with psychosis. By drawing on both the PTSD and the psychosis literature, we aim to identify psychological processes and symptom characteristics that may predict PTSD reactions after psychotic episodes.

Predictors of PTSD symptoms from non-psychotic events

Our starting-point was to identify from the literature predictors of PTSD for external events and then apply that knowledge to the understanding of traumatic reactions to the internally generated negative events of psychosis. Four predictors of PTSD from an external event have regularly been identified: helplessness, uncontrollability, lack of crisis support and a history of previous trauma (e.g. Brewin, Andrews, & Valentine, 2000; Joseph, Andrews, Williams, & Yule, 1992; Joseph, Yule, Williams, & Hodgkinson, 1994; Joseph, Brewin, Yule, & Williams, 1991).

The most widely found result is that a history of previous trauma is associated with the development of PTSD after a subsequent traumatic event (Astin, Ogland-Hand, Coleman, & Foy, 1995; King, King, Foy, & Gudanowski, 1996; Resnick & Kilpatrick, 1994). In a meta-analysis of 267 studies, previous trauma in both adult life and childhood was one of the strongest predictors of PTSD (Brewin *et al.*, 2000).

One way of conceptualizing the threat that an event presented is to examine the extent to which a person felt *helpless*. Helplessness is an individual's subjective perception of a traumatic event and is considered as a measure of the intensity or severity of the event. However, it is distinct from intensity in that it reflects an individual's subjective perception of a traumatic event (Joseph *et al.*, 1991) rather than an objective consensus judgment of the degree of danger. It is commonly argued that subjective feelings of threat, rather than objective threat, carry more importance in explaining traumatic responses. Empirical evidence consistent with a role for helplessness in the development of PTSD is provided by Joseph *et al.* (1994). They asked survivors of the Herald of Free Enterprise shipping disaster to complete the

Perception of Helplessness Questionnaire (PHQ) and found that feeling helpless during the event was strongly associated with traumatic stress scores as assessed by the Impact of event scale (IES; Horowitz, Wilner, & Alverez, 1979).

The *controllability* of the traumatic event may also be important in understanding PTSD reactions. Rachman's (1980) theory of emotional processing indicates that sudden, uncontrollable and unpredictable stimuli are particularly likely to give rise to emotional difficulties. Brewin (1984) therefore argues that re-establishing a perception of control over an event is integral to successful coping. Thus, the belief that an event could happen again and is totally beyond a person's control inhibits emotional processing. By analysing personal accounts of the Herald of Free enterprise disaster, Joseph *et al.* (1991) found that participants who reported a lack of control over the event combined with a sense of personal failure had higher IES scores.

The level of crisis support has also been identified as a factor in the development of PTSD (Brewin *et al.*, 2000; Fadden, 1998; Joseph *et al.*, 1992; Joseph *et al.*, 1994). Crisis support is conceptualized as support from friends, family and health care professionals that produces the feeling that one can confide in them without any negative response and that active emotional engagement with the person and problem is provided (Andrews & Brown, 1988). Joseph *et al.* asked survivors of two shipping disasters to complete the Crisis Support Scale (CSS). It was found that less crisis support was associated with higher IES scores three and twelve months after the disasters.

PTSD symptoms from psychosis

A history of previous trauma is a significant predictor of future PTSD. If psychotic episodes can produce strong negative reactions, then a similar hypothesis can be formed for them: the more psychotic episodes individuals experience, the more likely the individuals are to have symptoms of PTSD. On the other hand, it has been suggested that the initial challenge to the sense of self of a first episode of psychosis exerts the most emotional impact (Mueser & Rosenburg, 2003).

But is there anything about the nature of positive symptoms that will make PTSD symptoms more likely? At the simplest level, persecutory delusions may be more likely to lead to PTSD since they are inherently about threat (Freeman & Garety, 2000) and are associated with greater distress than other delusion subtypes (Appelbaum, Robbins, & Roth, 1999). However, persecutory delusions are one of the most common symptoms at admission and, in common with all traumatic events, they do not inevitably trigger PTSD reactions. We wished to identify aspects of the content of persecutory delusions that may be more likely to lead to PTSD type reactions. There is great variety in the content of persecutory delusions (Freeman & Garety, 2004; Freeman, Garety, & Kuipers, 2001). For instance, individuals vary in the degree to which they think their persecutor is powerful, the nature of the threat, the degree to which they could cope if the worst happened (i.e. the threat materialised) and the imminence of the threat. It is plausible that particular aspects of the content of persecutory delusions may be more distressing or traumatising than others (Freeman & Garety, 2004).

Study hypotheses

The aim of the study is to investigate potential predictors of traumatic stress in response to a psychotic episode. The first hypothesis is that approximately one third to one half of individuals who have recently experienced an acute non-affective psychotic episode but subsequently recovered will score sufficiently highly on the IES in relation to the psychotic episode to indicate that they would meet criteria for PTSD. The second hypothesis is that known predictors of PTSD reactions to external events, such as shipping disasters, will also be associated with PTSD reactions to psychotic episodes. That is, traumatic reactions to psychotic episodes will be associated with experience of previous trauma, greater perceptions of helplessness, perceptions of lack of control and absence of crisis support. The third hypothesis is that people experiencing first episode psychosis will have significantly fewer PTSD reactions associated with psychotic episodes than those who have had more than one episode. The fourth hypothesis is that trauma reactions will be higher in individuals with persecutory delusions compared with those experiencing other types of delusion. Finally, it is hypothesized that particular aspects of the content of persecutory delusions (e.g. the power of the persecutor) will be associated with traumatic reactions to psychotic episodes.

Method

Participants

Individuals who had had an episode of psychosis but were now in remission were recruited from adult mental health services in an inner London area. Referrals were sought for individuals who had been given a diagnosis of schizophrenia or related disorders of non-affective functional psychosis (codes F20-29) according to ICD-10 (World Health Organisation, 1992) by their consultant psychiatrists. The inclusion criteria were that these individuals had experienced a psychiatric admission or intensive home treatment as a result of an acute psychotic episode in the last 12 months but had subsequently been discharged due to the remission of symptoms. Exclusion criteria were: patients in the acute stages of their illness (as judged by their clinical team), a primary diagnosis of affective psychosis or insufficient command of English to complete the questionnaires.

Informed consent was sought from 41 individuals. One participant was excluded from the study, as she appeared too confused to give informed consent and did not satisfy the criterion of a low level of positive symptoms. Four individuals declined to be interviewed. Thirty-six individuals with psychosis agreed to participate.

Assessments

The Impact of Event Scale (IES)

The IES (Horowitz *et al.*, 1979) assesses level of current PTSD symptoms. It consists of 15 items. Seven items measure intrusive symptoms (thoughts, feelings and imagery) and seven items assess avoidance (avoidance of feelings, situations or reminders). Respondents are asked to rate each item on a 4-point scale according to frequency of occurrence in the past 7 days (0 *not at all*; 1 *rarely*; 3 *sometimes*; 5 *often*). IES scores can be used to categorize levels of PTSD (Devilly, 2004). These levels are subclinical (0 to 8), mild (9 to 25), moderate (26 to 43) and severe (44 to 75). However, the IES is not intended as a diagnostic tool and these ranges should only be viewed as indicative.

The IES was selected because it has demonstrated reliability and validity (Corcoran & Fischer, 1994), and has also been used in previous studies with acute psychotic episodes as the index event (e.g. McGorry *et al.* 1991; Shaw *et al.* 2002). Furthermore, the IES was used in the PTSD shipping disaster studies upon which this study draws comparisons (Joseph *et al.*, 1992; Joseph *et al.*, 1994; Joseph *et al.*, 1991).

The IES was completed in relation to the psychotic episode. Because treatment and symptoms often occur at a similar time, it is difficult to separate their contribution towards post-psychotic traumatic stress. Shaw *et al.* (1997) report that it is difficult to ascertain whether reports from patients of difficulties with ward staff were real or delusional and that their study participants often could not clearly distinguish between illness and treatment stressors. Consequently, participants in the current study were asked to consider the most difficult period of their psychotic episode as the index event. However, all participants included a clear delusional belief within their index event.

To ensure that participants reported frequency of traumatic stress arising from the psychotic episode rather than reporting current frequency of psychotic symptoms *per se*, an example was provided using participants' own explanations of the index event. For instance, the first item on the IES asks the participant to select either not at all, rarely, sometimes or often in response to the statement 'I thought about it when I didn't mean to'. If the participant described the event as 'the time I thought my parents were aliens', then the researcher would reply that the first question on the IES asks 'how often have you thought about the time you thought your parents were aliens when you didn't mean to during the last 7 days?'

Perception Of Helplessness Questionnaire (PHQ)

This measure was originally used in the Joseph *et al.* (1994) study. It consists of four items: I thought I was going to die, I felt paralysed with fear, I felt helpless, I prepared myself for the worst. Respondents were asked to rate how long they experienced those beliefs during the disaster. However, because the duration of the index event (psychotic episode) in this study varied, participants were instead asked how much they agreed with the statements (*strongly agree* = 1 to *strongly disagree* = 7). Scores could range from 4 to 28. A low score reflected an increased perception of helplessness. The original measure had a Cronbach's alpha (α) of .74; this adapted version had an α of .73, which is acceptable internal reliability.

Crisis Support Scale (CSS)

The CSS was also kept as closely as possible to its original form but modified to be appropriate for the current study (Joseph *et al.*, 1992). The questionnaire assesses support received both immediately after the disaster and about the level of support at the time of interview. Because in the current study, the time between the index trauma and the interview would not be uniform, it was decided only to ask participants about support they received during and immediately following the peak of their psychotic episode. For consistency, the CSS measured agreement rather than frequency. Thus, 'whenever you wanted to talk, how often was there someone willing to listen just after the disaster?' was changed to 'whenever I wanted to talk, there was someone willing to listen' (*strongly agree* = 7 to *strongly disagree* = 1). Scores could range from 7 to 49. Low scores reflect a perception of poorer crisis support. The original scale demonstrated a Cronbach's α of .67 (Joseph *et al.*, 1992) while this adapted version had an α of .71, which is acceptable internal reliability.

Perceived Control Questionnaire (PCQ)

The Perceived Control Questionnaire (PCQ) was devised for the current study given that there was no questionnaire available that specifically measured perceived control during a psychotic episode. Four statements were selected that were considered to assess perceptions of uncontrollability during the psychotic episode ('I felt in control of myself', 'I felt that I should have been able to control my thoughts but I couldn't', 'this experience may happen again and there is nothing I can do', 'I felt in control while I was in hospital/receiving intensive home treatment'). Participants were asked to rate their agreement with each statement (*strongly agree* (7) to *strongly disagree* (1) for Items 1 and 4; scores were reversed for Items 2 and 3). Scores could range from 4 to 28. Low scores reflect a decreased perception of control. The PCQ demonstrated a reliability of Cronbach's $\alpha = .50$. This is a poor level of internal reliability.

Stressful life experiences screening (SLES)

The SLES (Stamm *et al.*, 1996) is a 20-item measure that assesses trauma history using a list of 20 adverse events. An example is 'I have witnessed or experienced a natural disaster, like a hurricane or earthquake'. Each item asks participants to rate between 0 and 10 how much the event describes their experience, the stress at the time of the event (stress *then*) and the stress experienced at the present time (stress *now*). Scores are summed to provide three subscores and a total for the number of events experienced. Stress (then) was considered the most informative for the current study since it assesses how the event affected the participant. The SLES was selected because it is brief and has acceptable psychometric properties (Stamm, 1994; Stamm *et al.*, 1996).

Details of Threat (DoT) Questionnaire

The DoT Questionnaire was designed by Freeman *et al.* (2001) to assess the content of persecutory delusions in order to develop an understanding of the distress associated with such beliefs. The questionnaire is in two parts. The first part is an interview in which participants are asked questions about, for example, the type of harm that they thought was happening or whether the participant knew the persecutor. The second part of the questionnaire asks participants to rate seven aspects of their delusion on a scale between 0 and 10. The questions aim to quantify content aspects of the delusion that may be related to distress, for example, beliefs about the power of the persecutor, the severity of the threat and the participants' ability to cope with the harm. In Items 3, 6 and 7, a low score reflects adverse content of the delusion while in Items 1, 2, 4 and 5, a high score reflects adversity. Reliability statistics are reported in Freeman and Garety (2004). The tense of items was changed for this study so that participants could report their experiences retrospectively. Persecutory delusions at the time of the most recent episode were assessed (when they had been present).

Brief Psychiatric Rating Scale (BPRS)

The BPRS (Overall & Gorham, 1988) is an 18-item scale designed to assess overall level of psychiatric symptoms. It is designed to enable clinicians or researchers to rate symptoms of psychosis on a scale between 1 (*not present*) and 7 (*extremely severe*). The scale can be summed, clustered into positive and negative symptoms or individual variables can be examined separately. It is a well-established (Bech, Malt, Dencker, & Ahlfors, 1993) and well-validated interview measure (for reviews, see Faustman & Overall, 1999; Hedlund & Vieweg, 1980).

Procedure

Following demographic questions, participants were interviewed using the DoT. Participants then completed the PHQ, the PCQ and the CSS, followed by the IES and the SLES. They were then interviewed to enable completion of the BPRS. Participants were interviewed no sooner than one month and within twelve months following the conclusion of intensive treatment (range 30–365 days, mean number of days = 149.2, *SD* = 111.6).

Ethical considerations

Ethical approval was granted by a local research ethics committee and standard procedures for obtaining informed consent were used. The study was initially explained by a disinterested party and potential participants were given twenty-four hours for consideration about participation.

At the end of each assessment, participants were asked 'how distressing did you find it answering the questions you have just been asked?' (1 *not distressing at all* to 10 *very distressing*), and asked for suggestions to make it less distressing. Most participants did not find it distressing (mean score = 2.03, *SD* = 1.78, range 1–8, mode = 1, only three scored above 5) or suggest any major changes to the procedure. Any participant distress was initially contained by the interviewer. However, in the event of further distress, participants were encouraged to talk with their care coordinators who had been made aware that this may occur.

Analysis

Associations were tested using Pearson's correlations and a multiple linear regression analysis was conducted using the Statistical Package for Social Sciences (SPSS Inc., 2002, Chicago, Illinois, USA) for Windows (Version 11.5). Data were examined for normal distribution. Stem and leaf diagrams were examined for skew and variables tested with a one-sample Kolmogorov-Smirnov test (no significant results were revealed). All significance tests were two-tailed. Finally, Kurtosis scores were all below one, indicating normal distribution.

To test the hypothesis that participants with persecutory delusions would score more highly on the IES than those experiencing other forms, delusions were dichotomized by the author into *persecutory* and *other* using the Freeman and Garety (2000) definition.[1] Three participants reported that they experienced delusions but declined to describe them. Consequently, they could not be classified.

Results

Participant and treatment characteristics

The age of the participants ranged from 18 to 73 years, although there were a large number of younger people with psychosis (mean age = 34.11, *SD* = 14.98, mode = 24 years). Of the participants, 21 were male and 15 were female. Three participants described themselves as Black Caribbean (8.3%), four as Black African (11.1%), two as Asian (5.6%) and the remainder (75.0%) as White European.

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[1] *Readers are invited to contact the author if they wish to see a table of delusion descriptions and classifications.*

There were a low number of hospital admissions in this sample (mean = 1.81; *SD* = 1.97; range = 0 - 8). There were 9 (25%) participants who had never had an admission, while 20 participants (55.6%) had recently experienced a first episode of psychosis. Participants had been in hospital or under care from the Home Treatment Team for a mean of 65.89 days (*SD* = 78.67; range = 4 - 365). They had been discharged from that care a mean of 149.22 days ago (*SD* = 111.63; range = 7 - 365) and were interviewed a mean of 207.40 days (*SD* = 139.17; range = 32 - 483) after what participants considered the height of their difficulties.

BPRS scores demonstrated that participants' positive symptoms were in remission. A sample in an acute phase of psychosis would be expected to demonstrate a BPRS mean score of approximately 45 (Faustman & Overall, 1999) while this sample produced a mean score of 23.61 (*SD* = 5.74; range = 17 - 39). Positive symptoms were low or absent. Seven variables (somatic concern, grandiosity, hallucinatory behaviour, unusual thought content, suspiciousness, conceptual disorganization and disorientation) were summed and produced a mean of 8.94 (*SD* = 2.30; range = 7 - 16). Negative symptoms were slightly higher. Seven other variables (emotional withdrawal, blunted affect, anxiety, tension, guilt feelings, depressive mood and excitement) were summed and produced a mean of 13.17 (*SD* = 4.66; range = 7 - 26). All 36 participants had experienced delusions at the time of the psychotic episode. Nineteen individuals had had persecutory delusions.

Psychosis related post-traumatic stress symptoms

The first hypothesis was that individuals would report PTSD symptoms from psychotic episodes. A high level of acute traumatic stress was reported by study participants (see Table 1). There were five participants who were categorized as having subclinical PTSD reactions (13.9%), nine as having mild PTSD reactions (25.0%), 14 as having moderate PTSD reactions (38.9%) and eight as having severe PTSD reactions (22.2%). Thus, 61.1% (*N* = 22) can be considered as having a moderate or severe acute traumatic stress reaction to their recent psychotic episode. To ensure IES scores were not simply reflecting current positive symptoms, they were correlated with the total BPRS positive symptom scores. The association was non-significant.

Table 1. Summary data for main outcome measures (*N* = 36)

	Range	Mean	SD
Impact of Event Scale			
Intrusion	0–33	13.22	9.85
Avoidance	0–32	16.19	9.42
Total	0–65	29.42	17.06
Crisis Support Scale	15–46	31.42	7.78
Perceived Helplessness Questionnaire	4–28	12.28	5.97
Perceived Control Questionnaire	5–26	14.33	4.99
Stressful life events scale			
Then	0–83	28.33	22.88
Now	0–78	14.61	18.47
Number of events	0–10	3.94	2.31

Personal and trauma related factors associated with traumatic stress from psychotic episodes

The second hypothesis was that a greater perception of helplessness, lack of control, lower crisis support and experience of previous traumas would be associated with PTSD symptoms in reaction to psychotic episodes. The associations between these variables are shown in Table 2. Higher levels of helplessness and previous trauma and lower levels of control and crisis support were all significantly associated with higher levels of PTSD symptoms.

Table 2. Pearson correlations between the Impact of Event Scale and the hypothesized predictors

	Impact of Event Scale correlations			Intercorrelations between measures			
$N = 36$ scale	Intrusion subscale	Avoidance subscale	Total	PHQ	PCQ	CSS	SLES *then*
PHQ	−.65**	−.37*	−.58**		.39*	.11	−.52**
PCQ	−.50**	−.27	−.43**			.35*	.26
CSS	−.36*	−.34*	−.39**				−.03
SLES (*then*)	.48**	.49**	.55**				

$*p < .05$; $**p < .01$.
CSS = Crisis Support Scale; PHQ = Perceived Helplessness Questionnaire; PCQ = Perceived Control Questionnaire; SLES (*then*) = Stressful life experiences scale (stress then score).

The variables PHQ, PCQ, CSS and SLES *then* were entered into a regression analysis with IES total score as the dependent variable. Co-linearity diagnostics demonstrated that the items were sufficiently independent from one another (Brace, Kemp, & Snelgar, 2003). Using the enter method, a significant model was obtained, $F(4, 31) = 9.29$, $p < .01$, $R^2 = .55$, adjusted $R^2 = .49$. All the independent variables, apart from controllability, significantly contributed to the model (see Table 3).

Table 3. Multiple linear regression predicting Impact of Event Scale total scores

Predictor variable	β	t	p
CSS	−.31	−2.37	.024*
PHQ	−.32	−2.18	.037*
PCQ	−.11	−.79	.438
SLES (*then*)	.35	2.44	.021*

$*p < .05$.
CSS = Crisis Support Scale; PHQ = Perceived Helplessness Questionnaire; PCQ = Perceived Control Questionnaire; SLES (*then*) = Stressful life experiences scale (stress then score).

First episode psychosis versus more than one episode

To test the third hypothesis, those individuals experiencing their first psychotic episode were compared with the rest of the group on IES scores. The participants experiencing their first episode of psychosis ($N = 20$) reported a mean IES score of 22.05 ($SD = 17.24$). The participants who had experienced relapses ($N = 16$) had a mean IES score of 38.63 ($SD = 11.83$). An independent *t* test indicates that this difference is statistically significant, $t = -3.27$, $df = 34$, $p = .002$, CI: -26.86 to -6.28. People with first episode psychosis scored lower on the IES than the relapse group.

Traumatic stress from persecutory delusions compared with other types of delusion

The fourth hypothesis was that PTSD symptoms will be higher in individuals with persecutory delusions compared with those experiencing other types of delusion. The mean IES score for individuals with persecutory delusions ($N = 19$) was 32.42 ($SD = 15.92$). The mean IES score for individuals with other delusion types was 24.07 ($SD = 18.43$). An independent t test was not statistically significant, $t = 1.42$, $df = 32$, $p = .166$, CI: -3.65 to 20.36.

Associations of the content of persecutory delusions with subsequent traumatic stress

The content of the persecutory delusions ($N = 19$) was measured by the DoT. DoT items were correlated with IES scores (see Table 4). Higher levels of PTSD symptoms were significantly associated with higher perceptions of the power of the persecutor, greater ratings of the awfulness of the threat, inability to cope, thinking the persecution to be deserved and lower ratings of control over the situation.

Table 4. Details of threat scores and correlations with IES scores ($N = 19$)

DoT Item	Mean	*SD*	Range	Correlation with IES score
How powerful was the person(s) trying to harm you?	7.24	3.20	0–10	.38*
If the threat did happen how awful would it have been?	7.67	3.05	0–10	.35*
How well would you have coped if the threat had occurred?	3.00	2.90	0–10	−.48**
How much did you feel you deserved to be harmed in the way you have talked about?	3.00	3.77	0–10	.40*
How unfair was it that it was occurring to you?	7.14	3.38	0–10	.19
How likely was it that factors beyond your control may have lead to you being rescued from this harm?	3.86	3.95	0–10	.07
Overall, how much control did you have over the situation?	2.54	2.47	0–7	−.40*

*$p < .05$; **$p < .001$.

Discussion

In this study, we assessed current levels of PTSD symptoms associated with recent psychotic episodes and examined associations with potential predictive factors such as social support and the content of delusions. The aim was to develop the understanding of why some people have severe emotional responses to psychotic episodes.

PTSD symptoms in response to psychosis

A PTSD diagnosis needs to be established by clinical interview. However, the questionnaire assessment indicates that almost two-thirds of the participants were in the moderate to severe range for PTSD scores. The IES scores are similar to those reported in the studies of Frame and Morrison (2001), McGorry *et al.* (1991) and Shaw *et al.* (1997). It should be highlighted that in common with studies of PTSD following physical events (e.g. Breslau, Davis, Andreski, & Peterson, 1991), there is a large range in the IES data: it is clear that the occurrence of a psychotic episode does not invariably produce a PTSD response.

Potential predictors of PTSD symptoms

What were high PTSD symptom scores associated with? Participants who reported being more helpless and in less control during the episode and perceived their social support to be of lower quality had higher traumatic stress responses. Moreover, previous experience of traumatic events was associated with PTSD symptoms. It is also of interest that control and helplessness have a stronger association with intrusion than avoidance. All these associations are consistent with the literature on PTSD after non-psychotic events. Psychosis associated trauma is therefore likely to be understandable in terms of normal trauma processes.

The study also identified psychosis-related factors that may make PTSD symptoms more likely. A greater number of previous psychotic episodes was associated with higher levels of PTSD symptoms in relation to the current episode. Repeated episodes may produce a greater emotional response. There were also particular aspects of the experience of psychotic symptoms that were associated with PTSD symptoms. An examination of the content of persecutory delusions provided evidence that an increased perception of threat was associated with higher IES scores. For instance, traumatic stress was associated with judgments of the awfulness of the threat. Also associated with PTSD symptoms were lower perceptions of control over the persecution and the ability to cope. Furthermore, participants who rated their persecutors as powerful had significantly higher levels of PTSD symptoms. Again, this is consistent with a lack of controllability of events leading to poorer later adaptation. The prediction that people experiencing persecutory delusions *per se* would demonstrate significantly higher IES scores was not supported (though there were indications that a larger sample size may detect an effect). Clearly, other types of symptoms can be experienced as threatening even when there is no direct threat of harm and, conversely, not all persecutory delusions lead to PTSD symptoms.

Clinical implications

The relatively high rates of PTSD symptoms indicates that clinicians should be aware of and assess for the presence of such symptoms in individuals with remitted psychosis. More speculatively, the data indicate that good quality crisis support has the potential to reduce post psychotic PTSD symptoms. Mental health services that provide support that includes listening empathically to delusional experiences and enhancing pre-existing support mechanisms (see Burbach, 1996) may be particularly helpful. Employing cognitive strategies to reduce personal feelings of guilt and blame may increase the ameliorative potential of social support. Furthermore, the results reinforce the importance of clinicians focusing on key aspects of delusion content. Working within delusional belief systems, discussing the parts of the delusional systems associated with the most distress, may be especially helpful (Fowler, Garety, & Kuipers, 1995; Freeman *et al.*, 2001). Employing cognitive techniques that target feelings of helplessness during acute stages of psychosis may reduce subsequent traumatic stress, while developing relapse drills (Birchwood, Jackson, & Fowler, 2000) may increase a subjective sense of greater control during future episodes.

Finally, it is cautiously speculated that traumatic stress and psychosis can, on occasion, be maintained in a bidirectional feedback loop mediated by the deterioration of social networks, substance abuse and poor service engagement. Firstly, there is evidence that becoming psychotic can result in post-traumatic stress symptoms (e.g. Frame & Morrison, 2001) and that more than one episode of psychosis is associated with higher traumatic stress. Secondly, it has been demonstrated that previous trauma is predictive of intensity and chronicity of psychotic symptoms (e.g. Bebbington & Kuipers, 1992) and that previous traumas are associated with psychotic illnesses (e.g. Mueser *et al.*, 1998). Evidence from the current study suggests that some people avoid reminders of their psychotic episode such as treatment related stimuli. Furthermore, Mueser, Rosenberg, Goodman, and Trumbetta's (2002) model of PTSD from previous traumas and severe mental illness postulate that PTSD can lead to substance abuse and deterioration of social networks, increasing the likelihood of psychotic relapse. The trauma literature clearly demonstrates that individuals are at increased risk of revictimisation (e.g. Turner, McFarlane, & Van der Kolk, 1996). Therefore, some people may become caught within a vicious cycle of psychosis and negative reactions. A therapeutic approach that is focused upon the confluence of psychosis and PTSD, particularly in the first episode, may yield significant clinical benefits.

Limitations

There are further notes of caution in interpreting the study findings. It is possible that the rates of traumatic stress were exaggerated. Care coordinators may have been selecting potential participants – the sample cannot be considered representative – and it should be remembered that the IES is not a diagnostic tool. It is noted that instructions to participants were complicated and it is possible that they may have misunderstood what was required. Furthermore, the IES ignores the hyperarousal aspect of PTSD and results may have differed had this been taken into account. It is also the case that levels of PTSD symptoms may change with longer follow-up. PTSD symptoms have been found to greatly remit after six months with no intervention (Kessler, Sonnega, Bromet, Hughes, & Nelson, 1995). Finally, the nature of the relationships between the variables cannot be determined by the study design. Higher levels of current emotional distress may have biased judgments of the psychotic episode and subsequent events. Our study indicates that what are needed are representative prospective studies with multiple follow-ups of PTSD reactions in psychosis.

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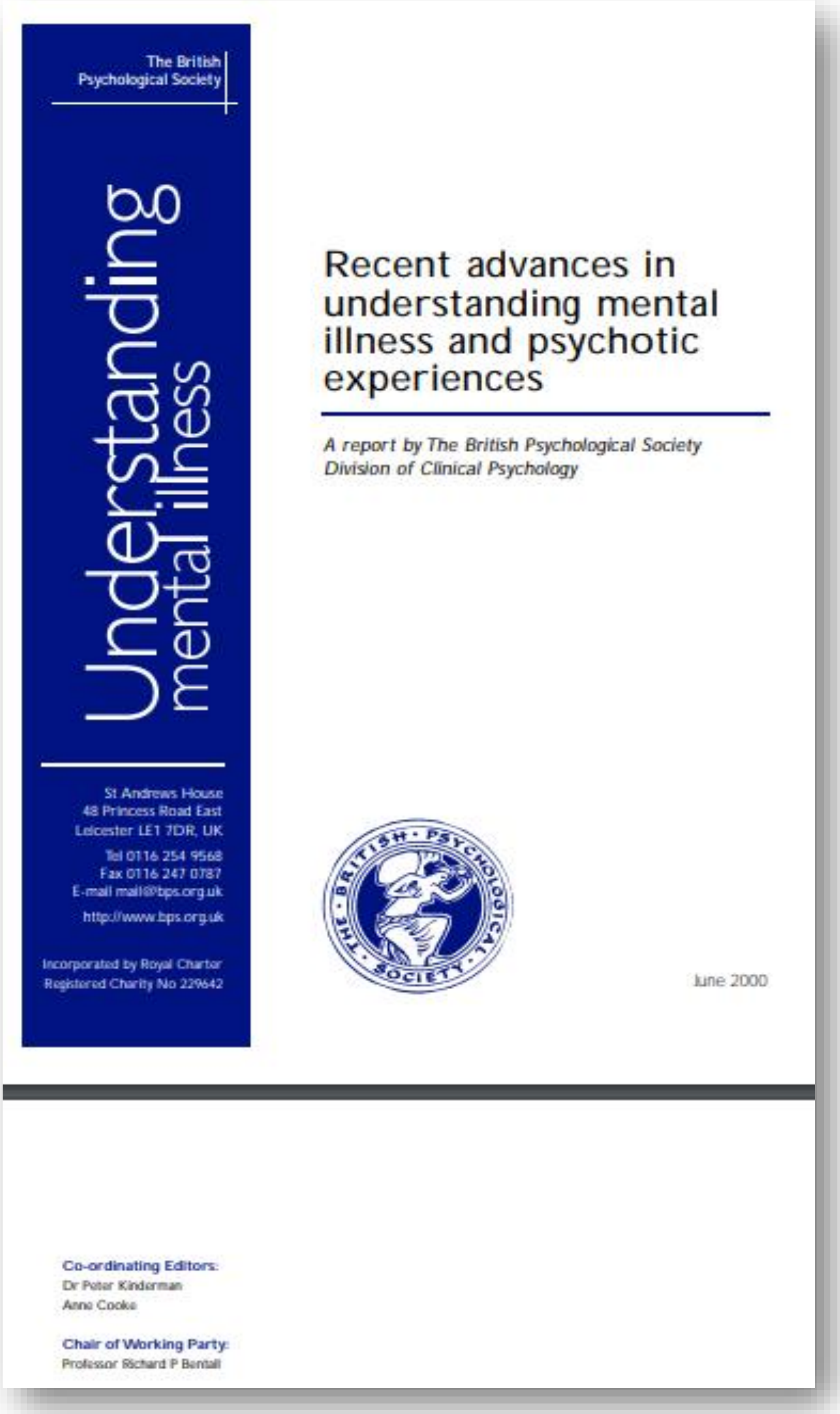

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