The Power Threat Meaning Framework

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London, January 12th 2018

#PTMFramework

(Slides: © Lucy Johnstone and Mary Boyle 2018)
Overview of the day

9.45 – 11.30   Principles of the Framework
11.30 – 11.55   Tea break
11.55 – 1.00    Practical implications of the Framework
1.00 – 2.00     Lunch
2.00 – 2.20     Service user perspectives on the Framework
2.20 – 2.50     Questions
2.50 – 4.10     Discussion, trying it out
4.10 – 4.30     Final round-up
4.30 -          Tea and networking
DCP Position Statement on ‘Classification of behaviour and experience in relation to functional psychiatric diagnosis’ (DCP 2013):

‘The DCP is of the view that it is timely and appropriate to affirm publicly that the current classification system as outlined in DSM and ICD, in respect of the functional psychiatric diagnoses, has significant conceptual and empirical limitations. Consequently, there is a need for a paradigm shift in relation to the experiences that these diagnoses refer to, towards a conceptual system not based on a ‘disease’ model’
The Power Threat Meaning Framework

DCP-funded project to take forward Recommendation 3 of the Position Statement:

‘To support work, in conjunction with service users, on developing a multi-factorial and contextual approach which incorporates social, psychological and biological factors.’
Contributors to the project over a 5 year period

Lucy Johnstone, Mary Boyle, John Cromby, Jacqui Dillon, Dave Harper, Peter Kinderman, Eleanor Longden, David Pilgrim, John Read, with editorial and research support from Kate Allsopp

Consultancy group of service users/carers
Critical reader group to advise on diversity
Other expert contributions
Good Practice examples
The Power Threat Meaning Framework: Towards the identification of patterns in emotional distress, unusual experiences and troubled or troubling behaviour, as an alternative to functional psychiatric diagnosis

The main document, available online only.
www.bps.org.uk/PTM-Main

Detailed overview of philosophical and conceptual principles; the roles of social, psychological and biological causal factors; SU/carer consultancy; and the relevant supporting evidence.

Chapter 8: Ways forward: Implications for public health policy; service design and commissioning; access to social care, housing and welfare benefits; therapeutic interventions; the legal system; and research.
The Power Threat Meaning Framework: Overview

The printed version.

Online at www.bps.org.uk/PTM-Overview

This consists of the Framework itself (Chapter 6 of the main document)

Appendix 1: A guided discussion about the Framework (also available separately)

Appendices 2-14 Good practice examples of non-diagnostic work within and beyond services

Brief description of the PTM Framework which can be adapted for local purposes.
The Power Threat Meaning Framework

Is NOT:

• An official DCP or BPS model
• A replacement for all existing models and practices. It integrates many of them within a larger overall framework
• For professional or service use only
• About formulation, but narrative in a broader sense

It IS:

• A conceptual resource for everyone to draw on
• Complex and detailed
• A first stage - in need of work to develop the framework itself, and to translate it into practice
Moving beyond the ‘DSM mindset’......

Medicalisation – applying theories and models intended to understand the body, to people’s thoughts, feelings and behaviour.

Instead, we need a framework for understanding people in their social and relationship contexts....

.....which sees them as actively making choices and creating meaning in their lives, within inevitable bodily, material, social and ideological constraints.
...and a framework which also....

- Recognises that emotional distress and troubled or troubling behaviour are intelligible responses to a person’s history and circumstances
- Restores the link between distress and social injustice
- Increases access to power and resources
- Helps to create validating narratives which inform and empower by restoring these links and meanings
- Promotes social action
....but without getting stuck at these points

‘Everything causes everything’

‘Everyone has experienced everything’

‘Everyone suffers from everything’
We already have many examples of non-diagnostic practice (see Appendices).

At a one-to-one level we have alternatives to psychiatric diagnosis such as problem descriptions; formulations; constructs (Hearing Voices) and a range of non-Western conceptualisations of distress.

What we don’t have is a framework for identifying broader patterns of distress and unusual experiences. This is what we have attempted to provide.

These provisional patterns can be used for fulfilling the purposes of psychiatric diagnosis more effectively.
The main purposes of medical diagnosis

• Summarise the evidence about causal factors
• Reduce complexity by grouping similar types of experience together
• Suggest ways forward and interventions
• Provide a basis for research
• Provide a basis for administrative decisions such as commissioning, service design, access to services and benefits, legal judgements and so on
Instead of ‘What is wrong with you?’ the Power Threat Meaning Framework asks:

• ‘What has happened to you?’
  (How is **Power** operating in your life?)

• ‘How did it affect you?’
  (What kind of **Threats** does this pose?)

• ‘What sense did you make of it?’
  (What is the **Meaning** of these experiences to you?)

• ‘What did you have to do to survive?’
  (What kinds of **Threat Response** are you using?)
Although ‘Power, Threat, Meaning and Threat Response’ is a convenient summary, these elements are not independent but evolve out of each other.

‘Power’ implies both ‘Threat’ and ‘Threat Response’, and all of these are shaped by their Meanings. (This is not a new version of ‘biopsychosocial.’)
Identifying broad patterns of Meaning-based Threat Responses to the negative operation of Power can help us to construct individual/family/group/social narratives, inside or outside services, supported or not by professionals.

The Framework talks about ‘narratives’, stories and meaning-making in a more general sense, rather than formulation particularly.

It is broader than any specific model but can be used to expand/enrich existing models and practices.
While most mental health (criminal justice, welfare etc) work is aimed at the individual, we argue that meaning and distress must also be understood at social, community and cultural levels. Thus we see the PTM Framework as applying equally to understanding, intervention and social action in a wider sense.

This fits with a recent United Nations report recommending a shift of focus towards ‘power imbalance’ rather than ‘chemical imbalance’ (UNHRC, 2017, p.19).
Additional core questions – adaptable in practice

• ‘What has happened to you?’
  (How is **Power** operating in your life?)

• ‘How did it affect you?’
  (What kind of **Threats** does this pose?)

• ‘What sense did you make of it?’
  (What is the **Meaning** of these experiences to you?)

• ‘What did you have to do to survive?’
  (What kinds of **Threat Response** are you using?)

  ....*and with particular individuals, families or social groups:*

• ‘What are your strengths?’ (What access to Power resources do you have?)

• ...and to integrate all the above: ‘What is your story?’
Power and Threat
Changing the question......

From...
‘What is wrong with you?’

To...
‘What has happened to you?’
(How is Power operating in your life?)
Some definitions of power......

- The means of obtaining security and advantage
- Being able to influence your environment to meet your own needs and interests
- A socially situated capacity to control others’ actions
Biological or embodied power operates through the possession of socially valued embodied attributes e.g. physical attractiveness, fertility, strength, embodied talents and abilities, physical health.

Coercive power or power by force involves any use of violence, aggression or threats to frighten, intimidate or ensure compliance.

Legal power can involve coercion but also rules and sanctions supporting or limiting other aspects of power, offering or restricting choices.

Economic and material power involves having the means to obtain valued possessions and services, to control others’ access to them and to pursue valued activities.
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Interpersonal power refers to power within intimate, caring relationships, the power to look after/not look after or protect someone, to leave them, to give/withdraw/withhold affection etc.

Social/cultural capital – a mix of valued qualifications, knowledge and connections which ease people’s way through life and can be passed indirectly to the next generation in a kind of symbolic inheritance process.

Ideological power involves control of language, meaning, and perspective.
We look at how power operates in relation to:

• Childhood adversity
• Gender
• ‘Race’ and ethnicity
• Social class and poverty
Some contexts created by the negative operation of power.....

- Unpredictability and low control over important outcomes
- Entrapment – unable to escape aversive environments
- Conflict – intrapsychic, relational, social
- Negative constructions of you and/or your group, because meaning is in other people’s hands
- Repeated exposure to violence, aggression, humiliation, criticism etc
How did it affect you? (‘What kinds of threat does this pose?’)

- Relational – e.g. threats of rejection, abandonment, isolation
- Emotional – e.g. threats of overwhelming emotions, loss of control
- Social/community – e.g. threats to social roles, social status, community links, self in the eyes of others
- Economic/material – e.g. threats to financial security, housing, being able to meet basic needs
- Environmental – e.g. threats to safety and security, to links with the natural world – e.g. living in a high crime area or just a neglected and rundown area with no natural features
- Bodily – e.g. threats of violence, bodily invasion, physical ill health
- Value base – e.g. threats to beliefs and basic values
- Meaning making – e.g. threats to ability to create valued meanings about important aspects of your life/ imposition of others’ meanings
The particular importance of ideological power – power over language, meaning and perspective ....

- Probably the least visible and least acknowledged form of power

- It underlies the conversion of social contexts to intrapsychic characteristics

- It is part of every other form of power

- It is central to the experience of invalidation

- It shapes the sense we can make of aversive and threatening contexts, with implications for action
Some final points......

- Linking threat and threat responses to the operation of power highlights the inseparability of the social, psychological and biological – but in ways which offer very different possibilities for theory and action from the biopsychosocial or vulnerability-stress models.

- The less access you have to conventional or approved forms of power, the more likely you are to adopt socially disturbing or disruptive strategies in the face of adversity.

- Power also operates positively!
Meanings and Threat Responses

1. MEANINGS
2. THREAT RESPONSES
3. LINKING THREATS TO THREAT RESPONSES
‘What sense did you make of it?’ (What is the **Meaning** of these experiences to you?)

Human beings actively make sense of the world. Our behaviour is intentional and meaningful, and serves important purposes.

*But what do we mean by ‘meaning’?*

The individual meanings we create are complicated. Meanings may be constructed from various elements including:

- Language
- Memories
- Feelings and bodily responses
- Our environments and resources
- Expectations about what is ‘normal’ in a given society
None of these elements are just ‘individual’. For example:

- Language is learned through our interactions with others.
- Memories are affected by our experiences. Memories of painful or shaming events may be particularly hard to forget.
- Bodily reactions and feelings are shaped by our learned responses over time. We can’t easily choose how to feel or react.
- We all come from different environments and have different access to resources, which enable but also limit the meanings we make.
- How we ‘should’ feel (eg when something difficult happens) is shaped by dominant cultural ideas.

(based on work by Merleau-Ponty, Langer, Cromby, Gibson, Bergson, Vygotsky, Bruner, Fernyhough) Derrida, Saussure and others.)
INDIVIDUAL MEANINGS ARE NEVER JUST FREELY CHOSEN

Instead, meaning is both ‘made and found’ (Shotter)

Meaning is inseparable from:

• Our relationships
• Our bodies
• Threats from the impacts of power
• Our responses to those threats
• The expectations and messages of society and culture
These are not ‘symptoms’, but *meaningful* responses to threats. They are our attempts to adapt, survive, endure, and keep safe.

These human responses are both evolved and acquired. They are simultaneously a product of:

- present circumstances
- past experiences
- bodily (biological) capacities
- cultural and social standards and norms
- the possibilities and limitations in our environments
Threat Responses: some examples

• Preparing to fight, flee, escape, seek safety
• Submitting, appeasing
• Giving up (‘learned helplessness’, apathy, low mood)
• Being hypervigilant
• Having flashbacks, phobic responses, nightmares
• Having rapid mood changes
• Amnesia/fragmented memory
• Hearing voices (in some cases); dissociating, holding unusual beliefs....etc
• ..as well as socially-valued responses – eg overwork.
Threat Responses

Threat responses are *not random*. They reflect:

- What has happened to people
- How they have coped (what they did to survive)
- Their circumstances (what it was possible to do)

Threat responses are (or were) functional. In other words, they are attempts to deal with various threats, emotional, physical, or social, as well as threats to identity, relationships, community, values and meanings.
Grouping threat responses by function not ‘symptom’

For example:

*Regulating overwhelming feelings:* (e.g. by dissociation, self-injury, memory fragmentation, bingeing and purging, intellectualisation, ‘high’ mood, low mood, hearing voices, use of alcohol and drugs, compulsive activity of various kinds, overeating, denial, bodily sensations, bodily numbing).

*Protection against relationship loss, hurt and abandonment:* (e.g. by rejection of others, distrust, seeking care and emotional responses, submission, self-blame, interpersonal violence, hoarding, appeasement, self-silencing, self-punishment).
Why are the links between threats and responses not more obvious?

- The threat (or operation of Power) may be less obvious because it is subtle, cumulative, and/or socially acceptable.
- The threat is often distant in time.
- The threats may be so numerous, and the responses so many and varied, that the connections between them are confused and obscured.
- There may be an accumulation of apparently minor threats and adversities over a very long period of time.
- The threat response may take an unusual or extreme form that is less obviously linked to the threat; for example, apparently ‘bizarre’ beliefs, hearing voices, self-harm, self-starvation.
Linking Threats to Threat Responses (cont):

- The person in distress may not be aware of the link themselves, since memory loss, dissociation and so on are part of their coping strategies.
- The person in distress might have become accustomed to denying a link, because acknowledging it might have felt dangerous, stigmatising or shaming.
- This denial may be encouraged by social messages about:
  - personal blame, weakness, and so on.
  - personal responsibility, ‘pulling yourself together’, etc..
The training of most mental health professionals encourages them to work within a diagnostic model, which imposes a powerful expert narrative about individual illness/disorder.

There is widespread resistance in society to recognising the common and damaging impact of negative uses of power.

There are many vested interests (personal, family, professional, organisational, community, business, institutional, economic, political) in disconnecting threats from threat responses - and thus preserving the individual ‘illness/disorder’ model.
All this means that many people are almost never offered sound, evidence-based, alternative frameworks in order to make sense of their own and others’ distressing or unusual experiences.

‘Epistemic injustice’ – experienced by groups who lack shared social resources to make sense of their experiences, due to unequal power relations (Miranda Fricker.)

....and that’s where we come in!
What kind of evidence-based patterns emerge from integrating the influences of Power, Threat, Meaning and associated Threat Responses?

A detailed review of the evidence about Power, Threat, Meaning and Threat Responses allows us to outline a provisional set of broad patterns in distress. These offer what has been missing so far – a way of helping to construct individual/family/group/social narratives, inside or outside services, supported or not by professionals.....

...as well as to suggest alternative ways of fulfilling the other functions of diagnosis.
General Patterns within the PTM Framework

We have provisionally outlined 7 General Patterns which cut across:

• Diagnostic categories
• Specialties (MH, Addictions, Child and Adolescent, Criminal Justice, Health)
• ‘Normal’ and ‘abnormal’
• People who are psychiatrically labelled and all of us
These are patterns of embodied, meaning-based threat responses to the negative operation of power.

These patterns will always be overlapping, provisional and changing – because they are organised by meaning not by biology.

The patterns will always reflect and be shaped by specific worldviews, social, historical, political and cultural contexts and ideological meanings.
In Westernised countries or cultures, these patterns draw on struggles with Western norms and standards, such as to:

• Separate from your family in early adulthood
• Compete and achieve in line with social expectations (eg in the labour market; for material goods)
• Meet your needs within a nuclear family structure
• Fit in with standards about body size, shape and weight
• Fit in with expectations about gender identity and gender roles
• Fit in with accepted views about the ‘self’
• As an older adult – cope with loneliness and lack of status
• Bring up children to fit in with all the above
Seven provisional General Patterns

1. Identities
2. Surviving rejection, entrapment, and invalidation
3. Surviving insecure attachments and adversities as a child/young person
4. Surviving separation and identity confusion
5. Surviving defeat, entrapment, disconnection and loss
6. Surviving social exclusion, shame, and coercive power
7. Surviving single threats
The General Patterns are described in terms of *meanings.*
The General Patterns are described as *what people do, not what they ‘have’* - verbs not nouns - to reflect the fact that they represent active (although not necessarily consciously chosen or controlled) attempts to survive the negative operation of power.
People will vary in their ‘fit’ with one or more patterns – thus, general patterns will always need tailoring to the individual.
This allows us to include aspects that helped and protected, along with strengths, abilities, achievements, and access to material, relationship and social resources and supports.
Overlapping – there are not, and could not be, hard and fast boundaries about the ways human beings respond to adversities

Probabilistic - we can never predict exactly what meaning people will make of events, or how they will choose to respond

Not one-to-one replacements for diagnostic categories (there is no pattern for ‘personality disorder’ or ‘depression’)

Not explanations of specific ‘symptoms’ such as low mood or panic – threat responses are described in terms of their *functions*

Cutting across the usual boundaries of ‘normal’ and ‘abnormal’, ‘mad’ and ‘sane’, ‘symptom’ and socially-valued behaviour

**Characteristics of the patterns: regularities but no simple causal links**
Because the patterns are based on meaning at personal, social and ideological levels, they will always be to an extent, local to time, place and culture.

In non-Western or non-Westernised settings, patterns may be shaped by different social norms; eg perhaps by community rather than individual responses to distress; by different concepts of the ‘self’; and by different histories (eg of colonisation).

However, the core elements of Power, Threat, and Meaning can be found in all groups and societies; and human beings all rely on certain universal evolved human capabilities and threat responses.
The Power Threat Meaning Framework predicts that there will be widely varying cultural experiences and expressions of distress.

BUT it does not see these as bizarre, primitive, less valid, or as exotic variations of the dominant Western paradigm.

Viewed as a meta-framework, the basic principles of PTM apply across time and across cultures.

Within this, open-ended lists of threat responses and functions allow for an indefinite number of locally and historically specific expressions of distress, all shaped by prevailing cultural meanings.
‘Spirit possession’ is sometimes seen as equivalent to the psychiatric concepts of ‘psychosis’ or ‘dissociative disorder’. One version, ‘cen’, is found in Northern Uganda, where civil war has resulted in widespread brutality and the abduction and forced recruitment of children as soldiers. In this phenomenon, young people report that their identity has been taken over by the malevolent ghost of a dead person. ‘Cen’ has been found to be associated with high levels of war trauma and with abduction, and the spirit was often identified as someone the abductees had been forced to kill.

We could understand this within the Power Threat Meaning Framework without having to call it ‘schizophrenia’ or ‘psychosis’
The patterns help us to draw up personal, group and/or social narratives that restore meaning and agency, and along with this, have the potential to create hope, rebuild relationships, and promote social action...

...which don’t lose sight of the following aspects:
The entrapping effect of the dominant narrative of psychiatric diagnosis
The contradictions in combining psychiatric diagnostic narratives with psychosocial ones.
The role of social discourses, especially those about gender, class, ethnicity and the medicalisation of mental distress, and how these discourses can support the imposition of others’ meanings.
The impacts of coercive, legal, and economic power.
The nature and impact of power inequalities in psychiatric settings.
The prevalence of abuse of interpersonal power within relationships.
The role of ideological power as commonly expressed through dominant narratives and assumptions about individualism, achievement, personal responsibility, gender roles, and so on.
The mediating role of biologically-based threat responses.

The importance of function over ‘symptom’ or specific problem.

The role of power resources in shaping threat responses.

Culture-specific meanings and forms of expression.

Self-help and social action along with, or instead of, professional intervention.

The importance of group and community narratives to support the healing and re-integration of the social group.

Recognition of the personal and provisional nature of all narratives and the need for sensitivity and respect in supporting their development and expression.

A meta message that is normalising, not pathologising (either medically or psychologically): ‘You are experiencing an understandable reaction to threats and difficulties. Many others in the same circumstances have felt the same.’
This General Pattern in the Power/Threat/meaning Framework describes a broad pattern of threats and threat responses which give rise to core meanings of rejection, entrapment and invalidation.

There has often been prolonged interpersonal maltreatment, abuse, invalidation and neglect in situations of lack of control, dependence, isolation and entrapment. The person was/is powerless in the face of emotional and/or physical threat, while often being dependent on the perpetrators for survival. These situations may originate with carers who were not able to create secure early relationships due to their own social, material and personal circumstances, and/or to protect children from exposure to significant abuses of power; and/or they may occur outside the family of origin and/or in adult life. There is likely to have been significant traumatisation and re-victimisation as an adult.
Common meanings: lack of safety, fear, rejection and abandonment, shame, guilt, unworthiness.

Common threat responses: Various ways of managing overwhelming emotions; protecting relationships/attachments; maintaining control

Disabling aspects of the threat responses may be reduced and counteracted by other responses which draw on skills, strengths, material, relationship and social support, alternative narratives, and other power resources.
This is purely hypothetical.

To our knowledge there are no current attempts to move away from diagnostic categories in welfare rights or other systems of rights and entitlements.

However, the PTM Framework suggests there are already ways, and could be additional ways, of preserving people’s rights to welfare and services while avoiding the disadvantages of receiving a diagnosis.
The Current ‘Welfare net’ is not based on specific diagnoses
Decisions about rights and entitlements are social policy decisions based on social constructs. In theory, anything is possible.

From what material is the welfare net of entitlements and rights woven?
<table>
<thead>
<tr>
<th>Entitlement</th>
<th>Construct</th>
<th>Additional Criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social Care (and adult safeguarding)</td>
<td>“mental impairment or illness” (This includes mental conditions, and mental illnesses)</td>
<td>Unable to achieve “outcomes” impacting on “wellbeing”.</td>
</tr>
<tr>
<td>Welfare – unable to work</td>
<td>“health condition, illness or disability”</td>
<td>Impact on “day to day functioning”</td>
</tr>
<tr>
<td>Welfare – “disability”</td>
<td>“long-term health condition or disability” (based on “mental impairment”- substantial and long term effects)</td>
<td>Difficulties with activities of daily living and/or mobility.</td>
</tr>
<tr>
<td>Housing - homelessness</td>
<td>“vulnerable” (due to “old age, mental illness or handicap”)</td>
<td>Less able to “fend for themselves” than an “ordinary” person.</td>
</tr>
<tr>
<td><strong>Source</strong></td>
<td><strong>Construct</strong></td>
<td><strong>Rights</strong></td>
</tr>
<tr>
<td>------------------------------------</td>
<td>-----------------------------------------------------------------------------------------------------</td>
<td>-------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td><strong>Equalities Act 2010</strong></td>
<td><strong>Disability.</strong> Based on Physical or <strong>mental impairment</strong> which has substantial and long term adverse effect on ability to carry out normal day-to-day activities.</td>
<td>• Employment</td>
</tr>
<tr>
<td>(replaced Disability Discrimination Act)</td>
<td></td>
<td>• Accommodation</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Access to goods, services and facilities</td>
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<tr>
<td></td>
<td></td>
<td>• Reasonable adjustments</td>
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<td></td>
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<td>• Positive action</td>
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</tbody>
</table>
Key terms in these systems

‘Mental Impairment’
‘Disability’
‘Mental Illness’
‘Mental Health Condition’

• No reference to specific diagnosis
• Basic broad qualifying social construct – confirmed by a professional – either present or not.
• Followed by analysis of functioning
Hypothetical ways forward

Three Options

1. No change.

2. Make net bigger. Use existing constructs but amend their definition.

3. Create a new net based on new constructs.

As we move down list, solutions require more work but entail less compromise.
Option 1: No change

Pragmatic: Based on omission and unquestioned assumptions - e.g. that receiving a service from a CMHT implies ‘mental impairment’. Endorsement by a professional with power to do so
Amend and extend existing net: e.g. keeping ‘disability’ but amending its definition so not based on ‘mental impairment’.

Option 2: Make the net bigger

‘Recognizing that disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others’

‘Impairment’ is not further defined in the convention but the UN and the WHO use the following definition of ‘impairment’ in their programmes:-

‘Any loss or abnormality of psychological, physiological, or anatomical structure or function.’
Create a new welfare net – based on new constructs

A possible phrasing: ‘Experiencing temporary and enduring or regularly occurring severe mental distress’
• No suggestion that this is a permanent ‘illness’
• Can be ‘well’ not just ‘in remission’ (e.g. Slade and Longden 2015).
But would this replace one deficit based model with another?

You are ‘different’ (lacking in some way)

Therefore you can receive basic support or money
How can all citizens access basic resources to cope with periods of extreme distress without the humiliating requirement of needing to demonstrate ‘impairment’?

Universal Basic Income? This has pros and cons, depending on how it is implemented.
Asset Based Community Development

‘How to build communities of hospitality that have a genuine place of welcome for the people who’ve been pushed farthest to the edge, with their gifts at the centre’

Cormac Russell, Nurture development
Summary

• This is purely hypothetical. To our knowledge there are no current attempts to move away from diagnostic categories in welfare rights or related systems

• The current system of entitlements and rights is not based on specific diagnoses

• It is in theory possible to create a system based on alternative social constructs

• Do we want a system where people have to demonstrate how much they are suffering in order to be objects of charity who can then receive their basic human rights?
Common assumptions: Are they always accurate?

‘...of course I need to have some kind of working diagnosis, erm, otherwise my referral letter will sound [like] gibberish’ (GP)

‘I guess the benefit of a diagnosis is it can open doors to services’ (Psychologist)
We accept patients where intervention in primary care has been unsuccessful or where the severity or risks of the illness require specialised input. A referral should be made early in the pregnancy and at the latest, by the end of the second trimester in the following circumstances:

- Previous history of puerperal psychosis
- Diagnosis of bipolar affective disorder
- Diagnosis of schizophrenia
- Previous severe depressive episode or post natal depression requiring treatment in hospital or secondary care
- Moderate or severe antenatal depression or anxiety disorders
- Preconception advice
- Current puerperal psychosis-if suspected, urgent referral required

Exclusion criteria:

Women with a diagnosis of personality disorder, learning disability, eating disorder or who are known substance misusers unless they are also suffering from serious or complex mental illness.
Freedom of Information (FOI) requests were submitted to each of the 17 NHS mental health trusts in the NHS ‘North of England’ region

Broadly diagnostic services: 35
Problem-specific but non-diagnostic services: 5
Needs-led services: 2
Services that support specific life circumstances: 4
‘Single Point of Access’ 2
Making use of psychosocial adversity codes in ICD-10

Kate Allsopp and Peter Kinderman

‘A proposal to introduce formal recording of psychosocial adversities associated with mental health using ICD-10 codes.’

The Lancet Psychiatry, September 2017
Homelessness

- Z59.0 is a billable/specific ICD-10-CM code that can be used to indicate a diagnosis for reimbursement purposes.
- This is the American ICD-10-CM version of Z59.0 - other international versions of ICD-10 Z59.0 may differ.
Central London NHS Mental Health Trust

Of 26,462 individuals who had one or more recorded ICD-10 diagnosis (further research needed on those who don’t):

24,433 (92.3%) had no social code / diagnosis (psychiatric diagnosis only)

2,029 (7.7%) had any recorded social code / diagnosis

1,739 (6.6%) had a primary social code / diagnosis (psychiatric diagnosis secondary)

440 (1.6%) had a secondary social code / diagnosis
Some implications of the PTM Framework for research and for public mental health

NB Some of the terms and concepts won’t be familiar to everyone – due to time limitations, please see the section on research in the Overview. There is also a fuller discussion about research in the Main online document.
By structuring studies by diagnostic categories (or including them even if the study is structured differently) we inadvertently reinforce diagnostic constructs.

A single alternative to categories is unlikely; instead we need to both re-invigorate established paradigms and develop new ones.

Use methods most appropriate to the key question.

Focus on specific experiences rather than global categories.

View experiences as lying along a spectrum (e.g., continuum and dimensional models of distress).

Use reliable and valid constructs which link experience with social context (e.g., hopelessness, etc.).

A range of qualitative as well as quantitative methods.

Some implications for research.
Alternative measures to medicalized outcome scales

Rating scales based on goals, on problems using the person’s own words (Shapiro’s Personal Questionnaire), psychotherapy process etc

Alternative methods

Grouped single case designs rather than RCTs

A transtheoretical approach focusing on change processes rather than brand name therapies (e.g. ‘common factors’, ‘therapist factors’, the ‘placebo effect’ etc)

How might study designs change if we moved away from seeing psychotherapy as if it were a drug treatment – rather, a socially-situated healing practice?

Transdiagnostic approaches to therapy
Example: Moving away from medicalised ways of talking about distress

Need to research experiences as they are talked about in ordinary everyday language (e.g. ‘thinking too much’) in their social and cultural contexts from multiple perspectives: range of disciplines, service user researchers etc

This could linked with work on the social model of madness and distress (Beresford et al, 2016) and new developments in Mad Studies

Narrative approaches (Greenhalgh, 2016) offer possibility of linking individual narratives with broader narratives: people’s social networks, communities, organisations and policy levels
Research incentives need to change

Continued use of diagnostic categories is maintained by vicious cycles, institutional inertia and perverse incentives. For example:

**Research funders**: should address their implicit biases: for bio-genetic and diagnosis-based approaches rather than psychosocial ones; for aetiology rather than prevention and intervention (e.g. for psychosis respectively: £1.67m; £0.3m; and £0.19m-- MQ, 2015)

**Research groups**: Should move away from use of diagnostic categories and use the alternatives out there

**Journals**: Leading journals should not require use of ‘functional’ diagnostic categories given criticisms; they should demonstrate support for and acceptance of non-medicalised approaches

**NICE**: Often criticizes categories but then ends up using them to structure reports - should make stronger calls for alternatives

**Professional bodies**: Could show leadership given the level of inertia elsewhere
Public Mental Health implications

A continued year-on-year rise in use of medication (and individual therapy too)

Therefore we need to:

- engage in more preventative ‘upstream’ action to address the root causes of distress (e.g. income inequality)
- work with policy makers to identify ways in which inequalities and exposure to adversities can be reduced
- develop a range of preventative strategies and evaluate them
- increase access to resources (e.g. education, employment etc) which may increase people’s control over their environment, build social cohesion and trust and address a widespread crisis of meaning
- consider rethinking some of the assumptions on which neoliberal Western economies are currently based (e.g. materialistic consumerism, individualism etc).
What terms do we use instead of diagnostic ones?

We are not just talking about diagnoses, but a whole medical discourse (illness, disorder, symptom, remission, relapse, prognosis, etc..)

This language serves important social purposes (defining certain people or actions as unacceptable, etc.)

Changing the language meets resistance because it threatens to reveal all these functions, and challenges existing forms of knowledge and the practices that depend on them (applies to some extent across all MH professions)
Without a rethink of the whole medicalised discourse and its assumptions – such as we have tried to offer – new terminology will simply perpetuate existing practices.

In the PTM documents we have alternated between emotional/psychological distress, problems, emotional difficulties, unusual experiences, and troubled or troubling behaviour.

Yes it’s complicated...For eg, labels are often applied to people who are ‘distressing’ rather than ‘distressed.’ But that reflects the complicated reality.
... or else we are perpetuating the idea that there is a ‘thing’ to be labelled – probably a medical ‘thing’

Eg ‘psychosis’ for ‘schizophrenia’; ‘mental health’ for ‘mental illness’

(although some existing terms may be preferable to others)

.....Even the new trauma-informed language such as ‘Complex Trauma Disorder’ proposed for ICD 11 doesn’t get us where we need to be
‘Problem descriptions’ using ordinary language (hearing voices; having suspicious thoughts; feeling suicidal; self-injuring)

These are loose terms but they are just as reliable as pseudo-medical concepts. We only need the terms to be reliable enough to meet our purposes....

....and in fact research and practice based on ‘Hearing Voices’ has arguably been more productive than any diagnostically-based studies or projects in the last 50 years.
The Framework and the evidence it draws from suggests that ‘symptoms’ and diagnoses describe ways of coping, not ‘conditions’ (either medical or psychological).

That is: what people do – not what they have.

This is captured in the titles of the General Patterns: eg ‘Surviving rejection, entrapment and invalidation.’

Possible ordinary language versions: ‘Grieving’; ‘Coming to terms with abuse’; ‘Having relationship difficulties’; ‘Struggling with social exclusion’ ... or terms that imply such processes and can be seen as shorthand formulations (eg bereavement; trauma reaction; spiritual crisis)
We have lots of ordinary words in everyday life for ‘clinical depression’ – misery, despair, desperation, and so on. Similarly, there are lots of alternatives to ‘patient’ – service user, survivor, client, expert by experience, etc. Instead of ‘a new dogma’ we need ‘sensitive diversity in language’ (Beresford et al, 2016.)

Different terms for different people, situations and purposes.
In their own lives, people should always be free to make their own language choices – which may include ‘illness/disorder’ ones.

(Although the choice NOT to use medical terms is rarely offered in services... indeed it may be punished.)

In the current system, some use of diagnostic language may be unavoidable to ensure access to benefits, services etc – rights that must be protected

(Although these terms are just as often used to exclude people – eg ‘borderline PD’)

Professional language use vs personal choices
AND: since it is acknowledged at the most senior professional levels that the current psychiatric diagnostic system is not scientifically valid or evidence-based (which is why it is being re-written from scratch) –

‘...it can no longer be considered professionally, scientifically or ethically justifiable to present psychiatric diagnoses as if they were valid statements about people and their difficulties.... These can no longer be professionally-sanctioned concepts’ (PTM Overview, p. 85)
It is anxiety-provoking to move away from the false certainty offered by diagnosis...doing so presents us with the many painful personal and social realities that diagnosis obscures....

...but in working together to develop new ways of naming and talking about people’s experiences of distress, we also bring into being new understandings, new possibilities, new ways forward.

Changing our language: A simple but radical step that we can all take!
A Twitter question highlighted the following issues:

**Complex trauma/Trauma-informed therapy service/trauma liaison centre etc**

But what about people who don’t identify as having experienced a trauma? How do we define ‘trauma’ anyway? Does this distinguish people who have been labelled ‘PD’ from everyone else? Are such distinctions valid anyway? If you had a trauma-informed service, would you even have separate ‘trauma’ pathways?

If it is still a ‘PD’ service in all but name, how much of an improvement is this?
Thinking about what the pathway is for:

The Healing Network/ Integrated care

Getting away from medical or psychological language altogether:

Rediscovery service/New perspectives/The Listening Centre

Are these specific enough? And if not, does it matter? And are we actually offering what the name implies? And what are the service users’ views?

Answer: There is no single or simple answer but the process forced us to think – about what we are doing, what we want to do and why, and what kind of changes we need to make in addition to the name.
The PTM Framework was co-produced with the survivor members of the core team from the beginning. It draws extensively from survivor literature and has benefited from other SU contributors.

In addition, we consulted with a group of 8 service users/survivors and carers. They were sent a brief outline of the Framework and then invited, via a one-to-one discussion, to reflect and give feedback on it from the perspective of their own lives, experiences and mental health difficulties.

Their comments were then used to refine the framework further. They were paid for their time.
Aiming for a range of backgrounds and experiences:

4 men 4 women

Age range 21-54

5 White British, 2 African Caribbean, 1 non-British (unspecified for the purposes of the project)

A range of diagnoses in childhood and/or adulthood from anxiety to ‘schizophrenia’

Most had not been exposed to ‘critical’ perspectives in any detail, and were not mental health activists or campaigners.
‘The most helpful aspect has been the power, and had this been up for discussion it would have changed the course of what happened...for me’ (E).

‘[The] power part of the framework is the fulcrum of it’ (F).

‘It would have felt like a weight off my shoulders to feel that the person I was talking to was recognising the things... that were predominantly the cause of my problems... somebody hearing me say, ‘I have absolutely had the sharp end of the stick in certain power-related situations ..........That would have been an incredibly helpful alternative to what did happen’ (C).
‘How did it affect you?’ (What kinds of threat does this pose?)

‘Threats’ included relationship traumas, poor housing, violent neighbourhoods, physical disability, welfare systems, racial discrimination and poverty.
‘Intuitively I always understood my experiences this way. How scared, suspicious and fearful I was made sense to me, I’d experienced various threats, including my first memory, pretty much constantly throughout my life in all the different spheres I existed, and another dramatic threat on the day I started to hear voices....My voices, constantly threatening to harm me, and berating me as justification for why they would harm me, felt like an expression of the fear I’d spent my life denying I felt, and mirrored the general pattern of threats I’d experienced.’
Consultants spoke frequently about the damaging impact of having others’ meanings imposed on their feelings and behaviour within mental health services:

‘...absolutely everything I had to say, including that the drugs were making things worse, [staff] made me, and more specifically my brain, the problem, rather than my traumatic experiences’ (F).

Consultants saw the processes of meaning-making and permission to speak as being linked, and as offering the potential for avoiding diagnosis, accessing more appropriate intervention, adopting more adaptive coping responses and feeling more positive about oneself.
B stated that it was extremely useful to provide a context for consciously exploring/addressing one’s responses to threat, and what the origins of these might be: ‘…..dealing with real things that are happening right now, rather than persuading [you that you’re] a bit crazy, take the pill, shut up about it.’
Consultant A approved of the simplicity of the framework (‘it is simple yet clever at the same time’), and how three discrete yet overlapping constructs could be used to capture ‘many different strands’ of one’s experience.

B felt the framework made an ‘enormous’ amount of sense and was ‘very strong and useful…and really, really helpful’, particularly the threat component. B also approved of the way that the framework facilitated open discussion of ‘unmentionable’ events and could help people feel a sense of permission to disclose: ‘that it’s okay to talk about these things, it’s okay to tell people about them...to name them.’
C felt that the framework made ‘absolute’ sense and covered issues of ‘huge relevance’ to the precipitation and maintenance of emotional distress.

C particularly approved of the way that the framework encapsulates broader sociological issues and applies these in a way that contextualizes individual, psychological concerns. C felt that this was ‘a major step forward’ as it is something so obviously absent from current DSM diagnoses.

C also felt the framework had implications for ‘social activism and challenging the status quo’ in the sense that it highlights the toxic impact of various forms of oppression and injustice.
Strengths of the PTM Framework

- preventing or making more difficult the imposition of others’ meanings
- giving ‘permission’ to speak about certain life experiences
- encouraging more positive and helpful coping responses
- partly as a result of this, potentially fostering a quicker ‘recovery’

If the Framework had been offered at first contact with services:

‘I can guess I would have felt stronger afterwards. To be able to see a professional... Ask me, genuinely, about any problems I’d had, power related situations or threat related situations... [and] telling me ‘these are absolutely valid things to be hugely unhappy about and very valid things to have suffered because of’ (C).
Queries and aspects to improve

- Language and conceptual complexity
- Possible additional threat responses
- Risk of interpreting as imposing another professional model
- Need for wider cultural change if the PTM Framework is to have an impact.

Consultant C pointed out that the PTM Framework could be problematic for people who might prefer a diagnosis which did not explore their personal history, and seemed to provide clear-cut answers rather than this more complex picture.
Possible uses of the Framework for service users/survivors/all of us

The Guided Discussion for personal or peer-supported use

Group support – in and out of services – with the aims of information-sharing, validating, creating new narratives, offering alternatives, promoting social action, making links with wider issues of social justice and equality

Restoring ‘epistemic injustice’ – experienced by groups who lack shared social resources to make sense of their experiences, due to unequal power relations (Miranda Fricker)
Public education – more effective anti-stigma campaigns?

Focussing on labels rather than people and their life circumstances increases fear and prejudice
Diagnostic labelling increases:

Perceived Dangerousness
Perceived Unpredictability
Perceived Lack of Responsibility for Own Actions
Perceived lack of ‘Humanity’
Perceived Severity of the Problem
Perceived Dependency
Pessimism about Recovery
Fear
Rejection
Desire for Distance

What does the research say would actually reduce stigma and discrimination?

1. ABANDON BIO-GENETIC EXPLANATIONS AND DIAGNOSTIC LABELS

1. INCREASE CONTACT WITH THE PEOPLE INVOLVED AND UNDERSTANDING OF THEIR LIFE CIRCUMSTANCES

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