Pioneer Scheme Day-release programme
Wednesday 24th May 2017
Horselethill Road, Glasgow

Chronic pain, trauma and shame

With Jonathon Tomlinson

Chronic pain and narratives

JT introduced us to his working life in Hackney and his links with poverty medicine, prison medicine and the Deep End. He talked about his cohort of traumatised Turkish patients (Turkey has more MRI scanners per capita than any other country), his family's experiences with chronic pain, understanding shame in illness behaviour, and the impact of these on his practice.

Art focus: Discussion around Frida Kahlo's self-portrait and Jonathon's blog *https://abetternhs.net/2013/09/07/pain/*

- In chronic pain there is a disconnect between the original mode of injury and pain sensations.
- As GPs, we can offer our expertise as one of the most consistent and continued forms of support that the NHS can offer to patients with chronic pain.

    - DO Match agendas. Value the patient's agenda and mitigate rejection.
    - DO Ask about how they live through a day or week - holistic approach and gain some continuity (for both dr and pt) with a diary.
        - Elicit the lived experience of pain and the linked phenomenology. Ask because you're Curious
        - But also Highlight days when they were better – what helped them in the past / what was good about that?
    - DO Share GP expertise of chronic pain
    - DO Distinguish from acute pain and why the approach to chronic pain has to, therefore, be different
    - DO be honest: "Might have it for the rest of your life" – we need to step out of the comfort of promising resolution (restitution theory)
    - DO explain "what something is, rather than what it is not"
    - DO share this link! https://www.painscience.com/articles/pain-is-weird.php and highlight Lorimer Moseley's TEDx talk

DIFFERENT ILLNESS NARRATIVES: HOW AND WHY THEY VARY AND THEIR IMPACT

Narrative medicine is an interdisciplinary pursuit of conversations to explore the patient's story with a view to optimal therapeutic outcomes.

Proponents Arthur Frank: The Wounded Storyteller
Rita Sharon: Honoring the Stories of Illness Rita TEDx talk
"Easier to talk about the disease you don't have than the stories you do..." J T Hart.

- Narrative accounts are the patient's interpretation of causes/ongoing problems
- Need to be cognisant clinicians – listen, examine and assess with careful scepticism in context of symptoms and findings.
- Critical reflection – Healthy scepticism of the 'sacred' narrative but anchored in justice, fairness and compassion.

- 'MIND THE GAP' – The (?unintended) information filter that clinicians impose
    - Testimonial injustice: e.g. Patient says "helpless endless misery" Doctor interprets "drug seeking behaviour"
    - Hermeneutical injustice: Clinicians filter patient's experience in the context of their available knowledge frameworks ('chaotic/ borderline' patient = ? actually traumatised but limited services for this!)
        - Havi Carel and James Kidd. Epistemic Injustice and Illness 2016 (http://bit.ly/2qQldBS)

- Narratives are co-produced: 'noisy' Interrupted by patient/professional/ Electronic records/ interpreter/ family/others.
- Narratives are produced for an audience and vary depending on the audience
- Patients seek help with validating their narrative – family support

- We need to harness new listening skills to truly tune in respectfully
    - Swinglehurst: Beyond the dyad (http://bit.ly/2rHfKxs)

- Important for Drs to have narrative humility
    - Make sense of the pt and drs experiences, avoid assumptions but actively interpret their narratives.
    - respect patient's self-identity (needing to be believed and accepted)
    - Patients remember 'doctors who KNEW them, really KNEW them'

- Help patients recognise the different drivers of their pain themselves
    - Dr: "*If you haven't slept / ate / upset, how are you then?"*
    - Dr: *So pain worsens when x y z happens?* Pt: *yes, AND when I'm low…*

NARRATIVES vary http://www.bmj.com/specialties/what-your-patient-thinking and are nuanced (Mike Bury: Illness narrative: fact or fiction http://bit.ly/2rAumN8)

Trauma and shame

Art focus: Adam and Eve leaving The Garden of Eden, Massacio c 1424, symbolism alive 700 yrs later with male emotional secrecy and female body issues.

Related reading: Hanya Yanagihara: A Little Life
James Rhodes: Instrumental
Leslie Jamison: The Empathy Exams

Shame impacts upon our health seeking behaviours.

- Shame: internalised stigma
- Prejudice: externalised stigma

Arthur Frank – how we experience our illnesses

- Restitution theory – resolution of illness – seeking cure
- Chaos theory – overwhelmed by intense illness – lived chaos can only start to be retold when the chaos is settling
- Quest theory – embrace for a higher alternative meaning eg coping / acceptance

As service providers, we risk presuming patients have complete control over their motivations and health behaviours, which is not the case. Institutions are not designed to support complex personality disorder / traumatised patients with parallel threads of illness experience.

ADVERSE CHILDHOOD EXPERIENCES AND THEIR IMPACT

1. Nadine Burke Harris TEDx talk http://bit.ly/2qR1ToW
2. CDC-Kaiser Permanente Adverse Childhood Experiences (ACE) Study. Available online http://www.ajpmonline.org/article/S0749-3797(98)00017-8/abstract

- Unique prospective study, identified that if 4 or more ACES or toxic stresses present = 4–12 x more likely to have mental health problems, addictions, suicide as well as risk of diabetes, obesity, smoking and criminal offending rises....
- Lifelong impact on how these children with toxic stressors develop maladaptation to people, health and relationships
- ACES TOO HIGH WEBSITE https://acestoohigh.com/about/
- Dunedin Birth Cohort study – prospective study of 1037 babies for 40 + years in New Zealand
    - http://dunedinstudy.otago.ac.nz
    - https://www.nature.com/articles/s41562-016-0005

THE TRAUMA WORLD AND DEFENCES

- Daniela Sieff https://www.youtube.com/watch?v=Hmg2ZIAnYLQ
- Unconscious hypervigilance, somatisation, heightened neuromuscular and emotional sensations
- Interferes with sensory stimuli, emotional parameters are distorted (accentuated for responses, muted for attachments)
- Behaviours
    - Embodied FEAR of re-traumatisation
    - Propensity to DISSOCIATE (emotional dissociation / develop addictions)
    - Identity becomes rooted in SHAME (you shift blame onto yourself)
    - Self-sabotage / protecting their history / sense of self

PROMOTING TRAUMA-INFORMED HEALTHCARE

Chaotic? 'Borderline Personality'? Walks Out Of Consultation? Frequent DNAs?
→ THINK OF TRAUMA!

Patient's shame and trauma

- RECOGNITION (and treading carefully)
- NON-JUDGEMENTAL approach
- Allowing space, asking for their permission to share
- Curiosity about their stories to understand their lived experience and challenges
    - What happens / how they cope/ how they make sense of this.
- Asking about loneliness (isolation but with cognitive baggage!)
- Do you blame yourself? (*yes)* … that must be so difficult - where does that feeling of self-blame come from? (*others treat me that way*) etc
- EMPATHY does not demand that we like all of our patients / their actions, but we need to share and understand their burden and be emotionally helpful towards them while providing a calm, positive space to heal.

Doctor's shame and trauma

- Being aware of one's own history and its impact on the care we provide
- Offering continuity and care can help self-empowerment
- Iona Heath: The Art of Doing Nothing http://bit.ly/2s8rvgS

PROVIDING TRAUMA-INFORMED CARE

- *Interpersonal*: A team with clear, visible, easy lines of communication where all staff are equipped to offer mutual support
- *Organisational:* patient's ease of access, welcome and toilets, wording of correspondence, lack of queues, ability to personalise patient care…
- *Material:* Premises, seating, music, professional non-threatening appearances, good quality trauma informed clinicians

KEY SUMMARY

- The role of Narrative medicine is growing in the management of Chronic pain
- Shame, trauma and ACEs distort how many patients present
- Trauma-informed care can only be effective if it is actively practised

14.00-16.00 – Roundtable discussion with JT, GP Fellows, Graham Watt, Andrea Williamson, Petra Sambale, Marianne McCallum, Lynsey Yeoman. Chair: David Blane

1. What are the CPD needs of Deep End GPs and how can we address these?
   http://www.gla.ac.uk/media/media_344426_en.pdf

- Therapeutic optimism maintained with realistic, evidence based medicine
- Patient engagement
- Patient participation
    - How do we make 'Patient Participation' welcoming for all?
    - (minimise self-selecting patients and widen scope)
    - Need to be able to see it makes a difference (publicise this)
    - Have open meetings, all invited
    - Have targeted themes (variety: digital online access, online consulting, young families)
    - Timing for accessibility for various patients
    - Feedback annual patient survey to help prioritise
    - 'You said… We did…' poster
    - Give them an expected timeline to see the effect
  - Appreciative enquiry – 'single or multiple long term condition' clinics, annual reviews and letters reworded. ? Looking for narratives.
  - 'House of care' models in Lothian, Tayside and Glasgow for CVD and diabetes
  - 'Always events' -The homeless health centre at Hunter Street ran a pilot: drop-in sessions and asking new patients what they would 'Always' like to happen when visiting GP.
    - Highlighted bullying outside
    - Some want to only be seen by a GP - mismatch between patient expectations and service as the centre offers any HCP
    - Interviewers conducting verbal interviews can help include patients who have literacy issues and identify 'always events' while minimising discrimination or exclusion.

2. VALUE OF THE DEEP END GP NETWORK

- ADVOCACY
- EVIDENCE (including practitioner experience)
- SERVICE DEVELOPMENT
- LEARNING NETWORK (MBBS/SSC/BSc/ELECTIVE/FELLOWSHIPS)

Deep end GPs since 2009 have established

- an authentic, consistent, persuasive voice and profile
- respectful collaboration on knowledge / expertise
- production of a repository of reports to allow lobbying
- used Aristotlean modes of persuasion
    - *ethos* (strong on credentials) - well organised, well informed voice and profile
    - *pathos* (contextualise to gain a sympathetic listener) - i.e. highlighting the relevance to the SG and other colleagues worldwide!
    - *logos* (appeal with strong logic)

- boost morale while bringing about (slow or fast) progress
- Medical students exposure to 'health inequalities day' at university (twice per year)
- Funding from SG for other projects
- GP steering group and workshops
- LINKS workers pilot Peter Cawston lead GP, pilot initially funding for 7 - then 40 more in 2017, then 200 after 2018 across Scotland
- Govan SHIP project
- Pioneer scheme
- Supporting CPD needs for existing and incoming deep end GPs
- Opening conversations with 'other service colleagues', GP academics, politically active GPs.

CHALLENGES AND SOLUTIONS FROM JT's HACKNEY PRACTICE + CCG

1. Turkish advocates (locally commissioned) bring the interpretative and social support for a traumatised patient cohort
2. Regular supervision for salaried GPs
3. Regular contact through the week daily when practice is closed '1-2 pm'
4. Regular CCG based learning opportunities on Fridays
5. Rewording letters to be less threatening
6. Empowering reception to understand about trauma related care
7. How to understand and engage with our own serious feelings related to our practice and producing a safe environment in which to debrief
8. Human factors in healthcare – spotting and eliminating discord in the team.
    - Martin Bromiley, an airline pilot whose wife died due to an anaesthetic complication in a routine surgical procedure.
    - Martin founded the Clinical Human Factors Group which puts human factors at the heart of patient safety and spreads awareness of how careful training and robust communication lines between all members in a clinical team will dramatically improve patient safety and critical outcomes.
    - https://www.youtube.com/watch?v=JzlvgtPIof4

Other recommended reading and actions:

- John Carnochan: 'Conviction: Violence, Culture and a Shared Public Service Agenda - Postcards from Scotland 9' *ISBN: 9781908931634*

- JT shared his personal experience and enthusiasm for an established and trusted Balint group to meet monthly or more to debrief on clinical and personal issues for GPs. PBSGL groups can perform a similar function.