Networking event - 19 October 2018

Discussion summary: Functional neurological disorders/symptoms

Key points

1. Require clarity of definition of functional neurological symptoms.
2. Variation in services across the country - criteria for acceptance; no services.
3. Solution Focussed Brief Therapy as an approach.
5. Unique value of occupational therapy - rapport; understanding the person - including spirituality; the unique skills occupational therapy bring versus problem focussed.
6. Treatment starts with education.
7. Functional assessments in context.
8. Our negative feelings as professionals - but also changing attitudes.
9. Importance of positive working relationships.
10. Importance of being believed.

Themes

MDT professionals

- Lack of understanding by MDT and professionals, knowing how to effectively treat.
- Different names/ terminology e.g. functional, somatisation.

Treatment interventions

- Having empathy with someone and not thinking 'stop it'.
- Difficulties with engaging clients, gaining co-operation.
- Need to educate the patient.
- What is the prognosis for these patients, patients often ask.
- Challenges of providing rehab in an MDT.
- Mistrust in the hospital setting and patients feel you don't believe them.
- Challenges of offering them equipment.
- Knowing what treatments to use.
- Concern about feeding into the problems.
- Lack of knowledge about what the best approach to treatment is.
- Importance of therapist, patient interaction.
- Identifying functional and personalised goals.
- Establishing trust.
- Do they need specialist teams?
- Often split the team.

Importance of education

- Patients not being given a clear diagnosis.
- Relatives not being given a clear explanation.
What are the causes of FND?

**Treatment setting**

- Lack of follow up and support.
- Challenges of assessing in the hospital environment and time constraints.
- No treatment pathway from acute to community.
- Challenge treating them in the acute setting when priority usually is trying to get patients discharged.
- Challenges of referring patients on.
- Challenges of long waiting lists for FND specialist rehab centres.
- Lack of psychology input.
- Lack of support to manage their psychological needs.

**Treatment**

- Psychology access.
- What is the best way to diagnose?
- Set small realistic goals, collaborative and intrinsically motivating.
- Needs a system approach.
- Not feeling believed.
- Try to observe in natural settings and in function.
- Neuro teams not commissioned for these patients and community services don't have the skills.

**Assessment**

- COPM
- MOHO
- Hopes for the future.
- Formal vs informal.
- Move away from medical model.
- Effort test.
- Video patient.
- You tube clips.
- GAS.
- VAS.
- Risk assessment.
- Goal setting.
- Importance of demonstrating progression.
- Hoover test.
- Use social model of disability.
- If it is related to PIP then different ball game.

**Occupational therapy skills**

- Physical and mental health divide - we use our mental health skills - emotional / psychological can be a 'turn off' to the MDT; in physical settings may not get referred to occupational therapy.
- Groundwork: engagement - motivational interviewing; time to talk; listening; rapport - explore issues.
- Working together / 'on board with you'.
- Solution Focussed Brief Therapy - lifestyle manual.
- Cannot explain diagnosis - therefore focus on 'function'.
- Education - explanation not great from neurologist - everyone needs more understanding - if cannot explain may take an easy way out; "I've changed over the years" and become more open/honest.
- More explanations given - respond better.
• Diagnosis as a starting point - e.g. patient accepted; response was a turning point leading to recovery.
• If there is a change in symptoms, people and MDT may question "are you sure it is not..?" and then goes back to consultant.
• Discharge from occupational therapy - what is acceptable to them?

Equipment

• How many people will use the equipment that we provide? Do we over prescribe? - consider the RCOT embracing risk document.
• But related to confidence of therapist - eg bathing equipment - Problems are real to them - so do we provide rehab or compensatory approach? - we use compensatory approach due to acute services pressures, and staff anxiety push for home with equipment. But occupational therapists can also explore further e.g. gait, then bathing transfers, then consider equipment but in context.
• If people report they are managing then don't worry about it.
• Example of a 20-year-old - inexperienced social services occupational therapist - provided equipment and telecare. Another occupational therapist went in and removed items - had conducted a task analysis with functional tasks.
• Advice: keep equipment to a minimum due to downsides to equipment.
• No services - community neuro rehab services won't accept; criteria requires 2 professions to be involved; require neuro diagnosis; require achievable goals - mental health teams may explore; mental health may not accept. Some community stroke teams have accepted onto caseloads.

Resource

• Geoffrey James - Solution focussed brief therapy.
• Glenn Nielson articles - Physiotherapist.
• Neurosymptoms.org - factsheets
• FND Hope
  http://www.FNDAction.org.uk