“Medically Unexplained Symptoms”
- an approach to rehabilitation

Prof Lynne Turner-Stokes

Herbert Dunhill Chair of Rehabilitation

King’s College London

Director, Regional Rehabilitation Unit

Northwick Park Hospital

What are we talking about?

- Patients presenting with
  - **Physical symptoms**
    - No obvious organic cause
  - **In addition, identifiable**
    - Psychological }
    - Emotional } Factors
    - Behavioural }
    - Psychiatric }

“Medically unexplained symptoms”

- Don’t like this term
  - **Implies we don’t know what’s wrong**
    - And can’t be bothered to find out
- Our job is to find out
  - **Discuss and explain it properly**
  - **Engage the patient and their family**
    - Establish what sort of help is appropriate
    - Make sure that they get it.

Why does it matter?

- Very common
- Generally badly managed
  - **‘Fat-file’ patients**
    - Engender frustration
    - Destroys pt / doctor relationship
  - **Potent cause of**
    - Ill-feeling
    - Litigation

Doctors' beliefs

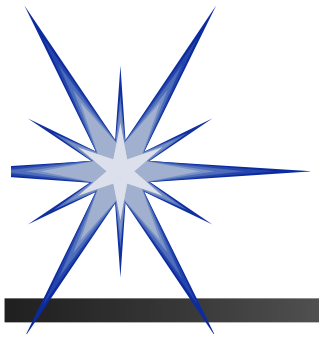
- Training
  - **Define disease in terms of pathology**
    - Cure disease by reversing pathology
- No identifiable pathology - Feel cheated
  - **Angry towards patients**
    - For misleading us
    - Behaving as if they have pathology when they do not
  - **Frustrated**
    - Our usual treatments will not work - cannot cure them
    - And worse - some do not even want to be cured

Establish a different attitude

- ‘Illness’ can be a social condition
  - **Engenders a caring response**
  - **Admiration from peers**
    - ‘Isn’t she brave!”
- Some who has found a prop
  - **Does not necessarily want it removed**
  - **Seek medical attention**
    - For confirmation - not cure
    - Diagnosis is an end in itself

Mis-interpretation of their approach

- Gives the wrong result
  - **Patient does not have their diagnosis**
  - **Doctor does not have their cure**
- Patient goes elsewhere
  - **Further investigation / medical costs**
    - Increasingly invasive
  - **Eventually falls into the wrong hands**
    - “Sir Cutler Walpole”



Terminology and diagnosis

Terminology

- Terms incorrectly used interchangeably
  - **Somatisation**
  - **Somatoform disorders**
  - **Functional somatic syndromes**
  - **Illness behaviour**
  - **Hypochondriasis**
  - **Hysteria**
  - **Malingering**

Somatisation

- Physical symptoms
  - **For which there are**
    - no demonstrable organic findings
  - **Positive evidence**
    - they are linked to psychological factors

Collective terms

- Somatoform disorders
  - **Psychatric diagnoses in which**
  - **Principle symptom concerns**
    - Preoccupation with physical symptoms
- Functional somatic syndromes
  - **‘Medically Unexplained’ Symptom clusters**
    - Different functional syndromes
      - Affect different bodily systems
    - Present to different medical specialities

Functional somatic syndromes

Gastroenterology	Irritable Bowel Syndrome Functional dyspepsia
Cardiology	Atypical chest pain
Neurology	Common Headache Chronic fatigue syndrome
Rheumatology	Fibromyalgia Complex regional pain syndromes
Gynaecology	Chronic pelvic pain
Orthopaedics	Chronic back pain

Beliefs and behaviours

- Illness behaviour
  - **Reaction to physical condition**
    - Out of proportion to the problem
- Hypochrondriasis
  - **Illness beliefs**
    - Excessive pre-occupation with disease
      - Really respond to reassurance
      - Pt continues to worry that they have serious illness
      - Despite clear evidence to the contrary

Insight and awareness

- Hysteria
  - **Patient presents with physical signs**
    - Often bizarre and no organic basis
  - **Truly has no insight**
- Malingering / factitious disorders
  - **Physical symptoms / signs**
  - **Intentionally produced or feigned**
    - For financial or other ulterior gain
- Two ends of a spectrum
  - **Elements of insight and volition**

Reasons for confusion

- **Clinicians afraid of getting it wrong**
  - Aware of limitations of ‘tests’
  - Difficult to be certain
- **Afraid of litigation**
  - Or upsetting the patient
- **Uncomfortable in broaching issues**
  - For which they are poorly trained
- **Reluctant to open “a can or worms”**
  - Which they do not have time to deal with

Prevalence and aetiology

Prevalence

- Medically unexplained symptoms
  - **Common in community samples**
    - General practice / New out-pt referrals
      - Up to 40% have symptoms for which no organic cause is identified
    - ‘Much less common’ in in-pt samples
  - **Majority of pts reassured**
    - Minority persist or develop other symptoms
      - Strong association between number of somatic symptoms reported and likelihood of underlying mental illness

Aetiological factors

- Childhood experience
  - **Illness**
  - **Lack of parental care**
    - Physical illness triggers care and attention which otherwise they would not receive
- Lack of social support
- Family re-inforcement
  - **Over-solicitous care or ‘helpful advice’**
- Iatrogenic causes

Iatrogenic causes

- Medicalisation of pt's symptoms
  - **Over-investigation**
  - **Inappropriate treatment**
    - Especially by more junior doctors
  - **Failure to provide clear explanation for symptoms**
    - Increasing uncertainty and anxiety
  - **Failure to recognise and treat emotional factors**

Consequences of somatisation

- **Unnecessary use of healthcare**
  - Investigations
  - Admissions for treatment / operations
    - Often making matters worse
- **Prescribed drug misuse and dependence**
- **Disability and loss of earnings**
  - Social disability payments
- **Poor quality of life**
  - Impact on family / social network

Functional somatic syndromes

Gastroenterology	Irritable Bowel Syndrome Functional dyspepsia
Cardiology	Atypical chest pain
Neurology	Common Headache Chronic fatigue syndrome
Rheumatology	Fibromyalgia Complex regional pain syndromes (Reflex sympathetic dystrophy)
Gynaecology	Chronic pelvic pain
Orthopaedics	Chronic back pain

What are the common features?

- Some symptoms associated with
  - **Increased sympathetic arousal**
  - **Mediated by autonomic pathways**
    - Butterflies in the stomach
      - Physical symptom of stress we all recognise
  - **Useful analogy**
    - To explain intensely physical nature of psychologically-induced symptoms
  - **Vasomotor disturbance**
    - in Reflex Sympathetic Dystrophy (CRPS) - skin colour / temperature
    - In chronic pelvic pain (congestion)

Spectrum of presentation

- Rarely ‘black and white’
  - **Patients present with a mixture of**
    - Physical }
    - Psychological } problems
    - Behavioural }
- The challenge is:
  - **To tease out the various components**
  - **Identify those which we can change**

Organic component

- Complete absence of organic disease
  - **Relatively unusual**
- More often
  - **Underlying organic ‘nubbin’**
  - **Needs to be identified**
    - Treated in its own right

Insight and Exaggeration

- Insight does not mean ‘malingering’
  - **Part of the normal human condition to exaggerate**
- Symptoms not life-threatening
  - **May not perceived as important**
    - May cause the best of us to amplify on occasion
- May or may not:
  - **have insight into this behaviour**
  - **be prepared to own up to it**
- Thrown a life-line
  - **Some will grab it**
  - **Others prefer to hang on to their symptoms**

Some patients

- Require their ‘medical condition’
  - **Part of own strategy for dealing with life**
- Come to clinic
  - **Not for a ‘cure’**
  - **For support and *bona fide* status**
    - Of ‘being under care of the doctor’
- Remove the crutch
  - **They will find another**

Secondary gain

- Disability may hold advantages for them
  - **Financial / Environmental**
    - Benefits, equipment, accommodation
  - **Support, care and attention**
    - From family , friends / carers
  - **Excuse for avoidance**
    - E.g of unwanted sexual attentions
  - **Social mystique or importance**
    - Having a ‘rare condition’

Recognise and contain

- Doctors who try to achieve great change
  - **Will be disappointed**
- Once identified
  - **Patients should remain in clinic**
    - Seen regularly, but not frequently
    - By the same senior doctor
      - Not left to junior staff
  - **Accept symptomatology and disability**
    - Without recourse to repeated investigations
    - Provide supportive interview instead (preferably with spouse present)
    - Approach demonstrably cost-effective (Smith et al 1986)

Real difficulty

- To identify those patients
  - **Who genuinely want ‘out’**
  - **Need an honourable excuse**
    - To surrender trappings of disability
    - Return to more normal function

Outline of approach to management and rehabilitation

Details given in report

Approach to management

- Identify features of organic disease
  - **Overlaying psychological elements**
- Establish degree of insight
  - **Extent to which they recognise**
    - psychological basis for their problems
  - **Extent to which they 'want out'**
- Determine the appropriate programme
  - **Physical / psychological / both**

Documentation is important

- Time-consuming process
  - **Important to document**
    - Pts tend to turn up in different places
  - **Acceptable language**
    - For defining the problems
    - Which everyone understands
    - Not defamatory
      - Patient's access to notes

Detailed assessment 1

- Define basis
  - **for suspecting non-organic pathology**
    - Positive identification of bizarre / inconsistent features
    - Detailed evidence of abnormal behaviours
- Determine exactly
  - **which features are believed to be non-organic**
    - Identify ‘nubbin or organic disease’
- Identify secondary gains
  - **Positive gains arising from their behaviour**
    - What would they lose if they abandoned it?

Detailed assessment 2:

- Level of insight:
  - **Are they open to the possibility**
    - That psychological factors play a part
  - **Or are they heavily defended?**
- Volitional component
  - **Are they feigning / exaggerating illness**
    - Or is it entirely unconscious?

Detailed assessment 3

- Do they ‘want out’
  - **Of all or part of it?**
    - Open acknowledgement of secondary gains
- What approach would be acceptable
  - **Recognised stress / psychological factors**
    - Cognitive behavioural programme
  - **Emphasis on physical problems**
    - Physical approach
      - E.g. graded exercise, practical multi-disciplinary approach

Avoid the following

- "I can't find anything wrong with you"
- "There's nothing abnormal to find"
  - **They will simply go elsewhere to find a better doctor who can find out what's wrong**
- Indicate what is wrong
  - **Both physically and psychologically**
    - Make sure they understand that this is an entirely normal and very common response to their condition

Components of inter-disciplinary approach

Medical management

- Reassurance
  - **Physical and occupational therapy are safe**
- Medical follow-up to avoid
  - **Seeking help elsewhere**
  - **Further iatrogenic damage**
- Symptom management
  - **Weaning off excessive medication**
- Support any litigation / compensation claim
  - **To its early conclusion**

Education

- Effect of
  - **Emotional stress** **}**
  - **Muscle tension** **} in increasing symtom**
  - **De-conditioning** **} experience**
  - **Their own behaviours** **}**
- Understand and accept self-management
- Teach skills
  - **Relaxation, breathing exercises**
    - To reverse sympathetic arousal

Psychology

- Identify and address psychological factors
  - **Contributing to symptoms and illness behaviours**
- Treat anxiety and depression
- Teach coping strategies,
  - **positive thought patterns, self-assertion, control**
  - **Inhibiting negative thoughts, catastrophising**
- Identify and challenge secondary gain
  - **Resulting in illness behaviours**
- Support family in withdrawing from caring role

Physical therapy

- Retrain normal body posture - guarding leads to
  - **bizarre postures**
  - **muscle tension**
- Desensitisation
- Progressive physical exercise
  - **Cardiovascular re-conditioning**
- Encourage
  - **Recreational physical exercise**
  - **Functional goals**

Occupational therapy

- Support graded return to
  - **Independence in activities of daily living**
- Adaptation of environment
  - **To maximise independence**
- Extend to social and recreational activities
  - **Outside home**
- Work-place assessment
  - **Vocational re-training**

The keys to success

- Not to expect miracles
  - **Any change is positive**
- Develop rapoor
  - **What is it that they want**