Diagnosis communication and patients’ coping strategies

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Patient focused quality interventions

• To improve health literacy
• To improve clinical decision making
• To improve self-care
• To improve patient safety

Coulter and Ellins. Effectiveness of strategies for informing, educating and involving patients. BMJ 2007;335:24-27
Examples of outcomes of interest

• Patients’ knowledge
• Patients’ experience
• Use of service and costs
• Health behaviour and health status

Coulter and Ellins. Effectiveness of strategies for informing, educating and involving patients. BMJ 2007;335:24-27
Diagnosis communication and patients’ coping strategies

Plan

• Emotional impact
  – Validated scales
  – Qualitative

• Coping

• What helps?
Disclosing the diagnosis of multiple sclerosis

• Majority of neurologists have good perception of their ability to manage this difficult communication process

• Believe in the great effect this moment may have on life-long disease experience

Communicating the diagnosis of multiple sclerosis

• The period surrounding MS diagnosis is very important. It is clearly remembered years afterwards.
• The MS diagnosis experience was varied; sometimes the level of support and provision of information was poor. However, improvement over recent years.
• Usually there was not enough time to discuss the diagnosis.
• The diagnosis must be delivered by a caring neurologist. The patient should decide whether a significant person should be present. Opinions regarding the presence of other health professionals varied.

Communicating the diagnosis of multiple sclerosis

• There should be privacy, time and support. If the diagnosis is disclosed in an inadequate setting the patient is left with an increased feeling of helplessness.

• The first encounter should provide the patient with further information on assistance and possibly with a schedule of other appointments within a short time.

• An overview of the disease should be given, but more specific issues need to be centred on the individual.

• The language should be simple, direct, and understandable to a newly-diagnosed person.

Communicating the diagnosis of multiple sclerosis

• The encounter should not be one-way. Professionals should always encourage feedback from patients.
• A diagnosis of MS may raise uncertainty, worry and anxiety that can be diminished by providing appropriate information.
• Not all the facts are necessary at once.
• Experience of using the internet to obtain information is often negative.
• Booklets published by MS societies, medical institutions, and pharmaceutical companies generally seen as very useful
• Appeals for funds by MS societies received badly by patients as they emphasise only the most shocking aspects of the disease.

Reflection on diagnosis after 5 years

• Initial concealment
• Adverse effect on confidence
• Uncertainty about future was disconcerting

Adjusting to early stage MS – describing diagnosis

- Distress and fear at diagnosis
- Overwhelmed by thoughts of being confined to a wheelchair and impending doom
- Seeking out more positive, optimistic information about MS increased
  - perceived ability to tolerate diagnosis
  - Perceived control over the disease

Dennison et al., Experiences of adjusting to early stage multiple sclerosis. Journal of Health Psychology. 2010;16:478-488
Adjusting to early stage MS – practical coping strategies

- Practical coping strategies for symptoms and limitations
- Learning to adapt behaviour and communication
- Social support deemed critical for adjustment
- Positive mental attitude fundamental for success
- Aim to carry on with their lives and minimise disruption

Dennison et al., Experiences of adjusting to early stage multiple sclerosis. Journal of Health Psychology. 2010;16:478-488
Adjusting to early stage MS – over time

• Many reach a point where MS co-existed with an acceptable QoL and emotional well-being

• But positive adjustment unstable
  – Subject to ongoing threats from MS
  – Only possible in context of no severe symptoms or relapses
  – Key threats were loss of ability to walk, drive, work and independence

Dennison et al., Experiences of adjusting to early stage multiple sclerosis. Journal of Health Psychology. 2010;16:478-488
After the diagnosis...

• Post traumatic growth
  – Quality of social support
  – Patients’ coping strategies
  – Patients’ personality
    • Expectations for positive outcomes
    • Higher perceived self-efficacy
    • Extraversion

What helps?
Evaluation of information aid for newly diagnosed MS patients

• RCT of diagnosis disclosure
• Current practice
• Current practice + information aid
• Personal interview with physician, CD and booklet
• Primary endpoint was MS knowledge and satisfaction with care

Solari et al., MSJ 2010;16:1393-1405
Patients reaching specified endpoint of MS knowledge and satisfaction with care

<table>
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Solari et al., MSJ 2010;16:1393-1405
Conclusions

- The uncertainty at the time of diagnosis is usually more stressful than the certainty of diagnosis.
- It is possible to schematize what patients need from professionals around diagnosis.
- Patient knowledge about MS can be formally evaluated.
- Information aids improve knowledge and satisfaction with care.
- Delivery of information needs to meet personal preferences and surmount logistical difficulties.
- Satisfaction with communication of MS diagnosis can be formally evaluated.