Illness Identities

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Introduction

A problem: Four months of fatigue (increasingly limiting normal activities)

Five outcomes from your GP

1. You have a virus infection; your fatigue will eventually improve but it may take anything between 6 months and a year; there is no treatment that will make any difference.
2. All the tests have come back normal; there is no explanation for your fatigue so at this point we should simply monitor things and wait and see
3. You have an underactive thyroid gland; you should start on replacement thyroid hormone and that should resolve your fatigue
4. You have a condition called Fibromyalgia – which causes fatigue and muscular pain. We can treat it with pain relief and a graduated exercise regime.
5. There are no abnormalities in your test results; this suggests your fatigue may be linked to external stressors – the best approach would be to see a counsellor or psychiatrist.

Discussion:

- Discuss which of these diagnoses you would prefer to get?
- Can you put them in order of preference?
- What makes one diagnosis more preferable to another?

Positives aspects of a diagnosis

Understanding

Validation

Treatment

Prognosis

Is it always good to get a diagnosis?

Overdiagnosis

Psychiatric (and psychosomatic) diagnoses

1. Differences compared to medical diagnoses

2. Overmedicalisation

We may mask the issue by defining les and less severe mood states as pathology, in effect saying, 'if it responds to an antidepressant, it's depression. Already, it seems to me, psychiatric diagnoses had been subject to a sort of 'diagnostic bracket creep' – the expansion of categories to match the scope of relevant medications.'

Peter Kramer, *Listening to Prozac*,
quoted in Mike Emlet, *Descriptions and Prescriptions*, New Growth Press 2017, p27

3. Biological approach and psychological approach

Many psychosomatic disorders start in the context of a major life stress. The physical symptoms are the consequence of real biological physical changes, but they are not due to a disease and would not have occurred without the stress trigger.

As a 'psychologiser', I hope that helping people to understand that something in their social environment has made them sick will give them control over how to deal with external stressors in the future. I fear that a view that talks too much about internal biological processes makes people passive victims of their medical disorder, which takes away their control. 'Biologisers' would say that placing too much emphasis on social and psychological triggers risks making patients feel they are being blamed for being sick. Neither approach is wrong.

My concern arises from how too much focus on biomedical research can distract from the many psychosocial factors invariably associated with mental health and behavioural disorders. The innate biology which creates vulnerability to mental health problems cannot always be changed, but the social and environmental factors can be.

O'Sullivan, Suzanne. *The Age of Diagnosis: Are Medical Labels Doing Us More Harm Than Good?* - (p. 194-5).
Hodder & Stoughton. Kindle Edition.

Discussion

- What kind of problems do you think might arise when a diagnosis becomes dominant in a person's life?

Negatives aspects of a diagnosis

1. Passivity

2. The illness role

3. Lowered expectations

4. Hyperfocus

5. Changed sense of moral responsibility

6. Constraining potential sources of help

Two life examples

Malcolm is a Christian believer. In his fifties he was diagnosed with autism. He got himself tested at the suggestion of his son, who had himself recently been diagnosed with autism. Malcolm had struggled throughout his career in insurance – there were frequent job changes which were usually precipitated by clashes with a colleague or a client. This diagnosis of autism made sense of his struggles – he had always found noisy and busy environments difficult and working in a team was just hard for him. He now saw that these were all autism related.
Malcolm does not like the deficit-based approach to autism and he objects to it being called a disorder. He prefers to identify the things that make an autistic person special. Rather than mask (that is, try hard to appear neurotypical) Malcolm believes autistic people should be their authentic autistic selves. He has become an advocate for autism in your church and champions for a whole range of changes to church services and events. 'Autistic people don't want to be fixed,' Malcolm says. 'Neurotypicals love to think autistic people are the problem but making us fit into your world is our real problem.'[1]

Naomi is a Christian believer. She has experienced ill health for over 20 years and gave up her administrative job more than a decade ago. She has moved back to her parent's home where she and her mother live off state benefits. Her symptoms began with a flu-like illness from which she never seemed to recover. Once the acute symptoms passed, she developed new symptoms including weakness of her muscles, a tingling sensation in different parts of her body and palpitations. She also developed brain fog which made it very difficult to read or focus on tasks. Sleep brought no relief – she woke just as weak and tired as before she went to bed. Despite a battery of tests, no firm diagnosis emerged. At one stage a doctor diagnosed Naomi with Lyme Disease and treated her with antibiotics. They helped at first, but then the antibody test came back negative and other doctors said it couldn't be the problem. Two years ago Naomi and her mother began reading about a condition called Myalgic Encephalomyelitis (ME) on the internet. The descriptions were a perfect match for Naomi's symptoms and they felt sure this must be the diagnosis. An online ME patient support group has provided wonderful support and is helping them set realistic expectations. Naomi has done extensive research into treatments for ME, but often struggles to find doctors willing to prescribe for her.

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[1] This description borrows some detail and this quotation from a person described by Suzanne O'Sullivan in *The Age of Diagnosis: Are Medical Labels Doing Us More Harm Than Good?* (p. 130). Hodder & Stoughton. Kindle Edition.

Discussion #1

- Suppose following a reshuffle of church small groups, Malcolm or Naomi became a member of the group you led. From past contact, you knew the rough outline above.
- How will you approach this meeting?
- Is there anything about your own heart you might need to consider?

Discussion #2

- Now suppose you had agreed to meet up with them regularly to try and help them think through this situation biblically, how will you go about this?

Some ministry principles

1. Don't be scared off!

2. Show patience and compassion

3. Begin with the good

4. Know them (and know how to pray)

5. Neither deconstruct them nor join their campaign

6. Treat the sovereignty of God gently

7. The glory found in our struggles (2 Cor 1:3-11; 1 Thess 1:6-10)

8. Rest on our eternal destiny in Christ

'*What no eye has seen,*
what no ear has heard,
and what no human mind has conceived' –
the things God has prepared for those who love him –
these are the things God has revealed to us by his Spirit. (1 Cor 2:9-10)

Dear friends, now we are children of God, and what we will be has not yet been made known. But we know that when Christ appears, we shall be like him, for we shall see him as he is (1 John 3:2)