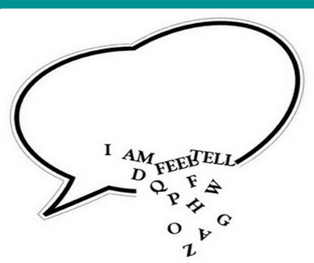


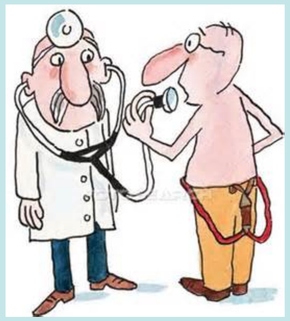
A Question of Communication: Does chronic illness cause muteness / deafness in medics?

Dr. Carole Gray carole.gray7@yahoo.co.uk

ABSTRACT

It is my, and many other chronic illness sufferers, experience that once you have been labelled with having a chronic illness members involved in the NHS fail to hear you when you speak. Other symptoms, concerns or illnesses presented become dismissed, understood as part of the existing malady or in worse case scenarios referred to as being in the patients' imagination. The pertinent question here is:-

Why can nobody hear us?



METHODS

In the abstract I talk about the data being pure data, of course this is a little tongue in cheek and an area I will clarify as opposed to defend.

In this setting, at this time, I am patient in the first instance and researcher in the second, I have a unique position of being analytic without sacrificing the data with more external accounts of 'what happened there'.

As Garfinkel, (Garfinkel, 2002: 175–176) would say this meets the 'unique adequacy' requirement for speaking on a subject and I would extend this by claiming patient as my master status.

Whilst difficult in this method of displaying evidence the poster will show extracts of the communication between medic and patient to elicit how communication breaks down and how it appears the patient is not being heard.

OBJECTIVES

- Analyse communication between medic and patient;
- Make explicit the 'talking' rules involved;
- Identify where these rules are used to effect
- Examine the outcome.

DATA

Me: *Can I just ask, I understand that graded exercise is advised in the literature, but I don't find it helpful, its too painful and seems to make me worse.*

Dr. *The recommended treatment is physiotherapy, c.b.t. and painkillers. This is what you have to do, this is what will make you walk better – do you not want to walk? Do you want to stay in a wheelchair for the rest of your life? If the pain increases we will give you more painkillers.*

Me. *But its worse and I don't like taking excess amounts of painkillers.*

Dr. *That's your only option.*

(meeting with doctor and physiotherapist 24 July 2001)

(following a conversation about changing medication 8 April 2003)

Me *… I've also got something wrong with my eye – its sort of like a flicker book effect – a bit sore but not painful.*

Dr. *I've no idea what that is. Let me know how you go on with the new tablets.*

(30 December 2011)

Me *I'm having trouble going to the toilet – I haven't had a poo for ten days .*

Dr. *I can give you a laxative*

Me *I've taken laxatives – I eat plenty of fruit and veg – I drink plenty.- I know there's poo there –it wont come out. I've been manually evacuating .*

Dr. *Carry on doing that and see how you go on.*

Me *I'm in quite a bit of discomfort*

Dr. *Carry on eating fresh fruit and veg and these things tend to resolve themselves*

Specialized Aerobic Sessions

Me *I tend to go dizzy if I stand too long*

Physio *these exercises are designed for people with your illness*

Me *I'll try*

Phsio *Are you ok? Carole, Carole*

The week after

Receptionist *Are you ok over there? Hello! Are you ok? Paul!*

Physio *I think we'd better knock it on the head – can't be filling incident report forms in weekly*

ANALYSIS

Asking 'permission' to ask a question is evidence of the asymmetry in the rights to talk and the power held by the parties.

There is an acknowledgement that the speaker is aware of what the 'cure' is supposed to be, but experience has provided the patient with further knowledge.

The doctor does not take this talk seriously which is demonstrated by a repetition of 'what they all already know'.

This is followed by a demand and a berating of the patient. This talk ratifies the asymmetry in power and lowers the status of the patient to one of 'person wanting to be ill.

This is an extended piece of talk permitted by the speaker's status. The doctor returns to the previous role of care giver in offering more pain relief.

The patient is ignored once more and the doctor initiates a conversation closer – 'that's your only option.' It is only through his status in the talk that he is able to do this.

The patient introduces a new topic – an area of concern.

The doctor acknowledges the topic and then reduces it to 'non-medical' by not knowing about it.

The conversation is closed by the doctor with a return to the previous topic. This acts as a closing statement. The opportunity to speak again is removed.

The patient makes a statement. Whilst it is not exactly a question the setting is 'one where you get medical help'.

In accordance with this, the doctor offers a prescription.

Is there a presumption that the patient and would not try the obvious? The patient outlines without being asked what remedies have been used .

No other option is given . To reopen the conversation the patient mentions the 'discomfort'. This is ignored by the doctor and the previous advice is reiterated.

This repetition of the same advice means that conversationally the patient can not ask again – the conversation has been ended by this utterance and the patient receives no treatment.

A statement by the patient – this statement was ignored - interactionally it was contradicted.

Medical 'knowledge v experiential knowledge'.

The lower status 'patient' means they have to comply or be seen to be difficult.

A question requires an answer – it does not receive one so a greeting is offered – this too demands a response – one is not provided so a reason is sought as to why – ignoring, didn't hear or in this case, fainted.

An enquiry – no response, a greeting is offered which requires a response too - an enquiry if something is wrong is offered followed by a request for help.

Recognition by the physiotherapist that perhaps the treatment is not suitable.

OUTCOME

2nd March 2011 & 1 April 2011

A visiting physiotherapist undertakes an examination and concludes that 'the wrong type of physio has been undertaken' and the result is 'hypertonia' which in this case presents as spasticity.

I am referred to an orthotic clinic for mobility aids as it is impossible to undo the damage. I have, clonus, dorsi flexion of the foot at the ankle which makes it irreparably damaged.

After 10 years on of trying to avoid various physiotherapy sessions it has become apparent I was right, they have caused damage and actually worsened my ability to walk.

Why did nobody listen?

Eye Hospital 9 November 2010

Tests found a loss of 48% of vision in left eye caused probably through the death of cells from oxygen starvation via_an autoimmune disease. Once destroyed the cells cannot be renewed found early enough there are treatments which may help.

After complaining for 7 years I find out what is wrong with my eye and how the sight loss was possibly avoidable.

Why did nobody listen?

January 2012

Self-referral to a clinic for colonic hydrotherapy – complications as there appears to be no sensation in the bowel or stimulus to contract.

13 February 2012

Referral for a gastroscopy – the bowel is impacted and the nerve responses are not working due to the continual administration of Morphine. A laxative must be taken daily if Morphine is prescribed.

I have been on Morphine for seven years – when I became chronically constipated why did nobody know this?

Nobody listened – why?

Referral to a 'new' aerobic treatment'

I am corrected when I say I have problems with this type of treatment.

I faint through standing too long

I faint whilst waiting for the physiotherapist, actually getting to the hospital is arduous enough

But nobody listens
