

Stopping the 'silent misdiagnosis'

▶ Patient preferences in healthcare sciences

▶ Dr Helen Pryce



Misdiagnosis

Medical – often followed up and known

Patient preferences-often hidden and ‘silent’

Diagnosis

Medical: we use test methods and systematically observe states and symptom reports.....we are trained to do this

Preferences: indirect and complicated ideas which may not chime with our own ideas, require complex listening and communication skills.....we are not always trained to do this

Evidence based healthcare

‘ Evidence based medicine means integrating individual clinical expertise with the best available external clinical evidence...

....and compassionate use of individual patient’s predicaments, rights and preferences in making decisions about their care.’

(Sackett, 1997)

Audiology

Tensions between biomedical interpretation
(we diagnose hearing loss, tinnitus etc in
specialist clinics)

And behavioural modification
(we import behavioural management as
treatments)

Which are informed by psycho-social
models of health

Patient preferences?

‘A preference mis-diagnosis is a silent mis-diagnosis.’

(Mulley et al, 2012)

Example – Archie Cochrane

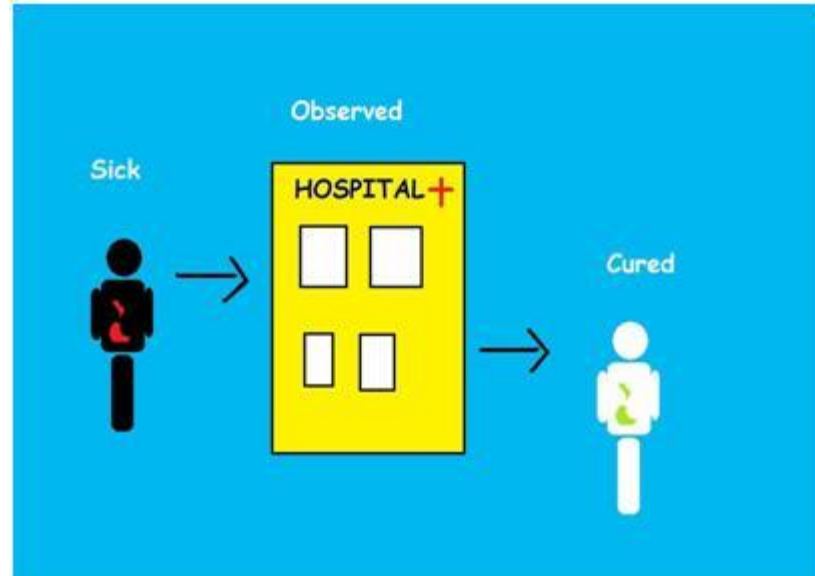
"Another event at Elsterhorst had a marked effect on me. The Germans dumped a young Soviet prisoner in my ward late one night. The ward was full, so I put him in my room as he was moribund and screaming and I did not want to wake the ward. I examined him. He had obvious gross bilateral cavitation and a severe pleural rub. I thought the latter was the cause of the pain and the screaming. I had no morphia, just aspirin, which had no effect.

I felt desperate. I knew very little Russian then and there was no one in the ward who did. I finally instinctively sat down on the bed and took him in my arms, and the screaming stopped almost at once. He died peacefully in my arms a few hours later. It was not the pleurisy that caused the screaming but loneliness. It was a wonderful education about the care of the dying. I was ashamed of my misdiagnosis and kept the story secret."

'The faulty machine metaphor'

(Wainwright, 2008)

Basis in biomedical approach to health



What are the problems?

Clinicians assume patients seek help to have symptoms removed

Little evidence that this is the case (Salmon, 1997)

Alternatively

Patients seek help to validate symptoms, get information and support

Entry to 'sick role' (Parsons 1964)

Hierarchy in illness

- Observable disease born bravely
- Observable disease with complaint
- Non observable disease born bravely
- Psychologically based illness
- Malingering

Common perceptions

- ▶ to suffer physically as a result of psychological distress is to lack moral fortitude (Salmon, 1997)

This influences our actions

- ▶ We test, assess and measure to identify and articulate ‘observable disease/deficit’ even if there is nothing that we can do with these observations
- ▶ We commission services which claim to remediate the faults in the machine...i.e hearing aids

And

- ▶ We become confounded when our scripts do not apply
- ▶ i.e tinnitus, APD/KKS, hyperacusis , chronic pain, fibromyalgia, pre menstrual syndrome (Mathers, Jones and Hannay, 1995)

What works?

- ▶ Positive encounters and good communication!
(Thomas, 1987)
- ▶ Being aware of our own needs and frustrations
- ▶ People need a name and an explanation to develop coping (Balint 1957)
- ▶ **LISTENING!!**

Shared Decision Making

- ▶ ‘No decision about me without me’
- ▶ ‘a reality, all along the patient pathway: in primary care, before a diagnosis, at referral and after a diagnosis’
- ▶ https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216980/Liberating-the-NHS-No-decision-about-me-without-me-Government-response.pdf

What information needs do people have?

- ▶ ‘You need to know what questions to ask’
 - ▶ ‘it’s a bit overwhelming’
 - ▶ ‘I’ve come to learn something’
-
- ▶ People seek help with hearing for information and to find out options (Pryce & Wainwright , 2008; Claesen & Pryce, 2012)

Information re hearing aids

- ▶ ‘they are uncomfortable’
- ▶ ‘it gets caught up in hair’
- ▶ ‘I don’t know if I’ve got a loop system’

- ▶ ‘she explained to me that they [hearing aids] probably wouldn’t help me’

- ▶ ‘Did anyone suggest anything other than a hearing aid?’’No’

Information for other options

- ▶ ‘ I like the idea of a group programme’
- ▶ ‘I don’t need anything special ..but in 10 years I might’

How do we do it?

Decision aids

Process (Laplante-levesque, Hickson, Worrall, 2010)



What choices do we give?

My hearing options				
What is it?	<u>Hearing aids</u>	<u>Group program:</u> Active Communication Education (ACE)	<u>Written program:</u> Individualised Active Communication Education (I-ACE)	<u>No intervention</u>
What is involved?	<ul style="list-style-type: none"> Being fitted with hearing aids. Wearing the hearing aids to help with my hearing problems. 	<ul style="list-style-type: none"> Participating in group sessions to learn ways to cope with my hearing problems. Using the information to help with my hearing problems. 	<ul style="list-style-type: none"> Reading chapters at home to learn ways to cope with my hearing problems. Using the information to help with my hearing problems. 	<ul style="list-style-type: none"> Keeping on going the way I am at the moment.
FIRST STEP Options I want to know more about <input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
SECOND STEP Options I will think about <input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Communication Disability Centre, 2009



Frequently asked questions	Hearing aids	Assistive listening devices	Coping without hearing technology
What does it involve?	Being fitted with hearing aids and wearing them	Using assistive listening devices such as a TV amplifier, a telephone with a volume control, a loop system or a louder door bell	Not having hearing aids Monitoring your hearing
What is expected from me?	Wearing your hearing aids regularly You can choose when to wear your hearing aids, but most people report more benefit from their hearing aids the more they wear them	Trying out and using assistive listening devices to hear specific sounds You can decide which sounds or situations are important to hear	Discussing changes in your hearing with your audiologist when you are ready You can learn ways to cope with your hearing difficulties e.g. communication training and lipreading
How will this help my hearing?	When you use hearing aids, your hearing may be improved e.g. in face to face conversations, when watching television	When you use assistive listening devices your hearing for specific sounds may be improved e.g. the television might be clearer	This will not help your hearing
What should I expect?	You may need some time to get used to hearing aids Some people find hearing aids difficult to manage with glasses	You will need to learn how to use the assistive listening device	Your hearing difficulties may be frustrating to you and the people you talk with
Are there situations in which this option will not help?	When you use hearing aids in noisy situations it can still be difficult to understand speech	Your assistive listening device will only help you hear specific sounds Some assistive devices are not portable	Does not apply
Do I have to pay?	NHS hearing aids and batteries are free	Yes but you can try first before paying You will need to pay for batteries	Does not apply
What maintenance is involved?	You will need to clean and maintain your hearing aids as well as change batteries and tubing regularly	You may need to change batteries regularly	Does not apply
Can I use more than one option?	Hearing aids can be used alone or with assistive listening devices	Assistive listening devices can be used alone or with hearing aids	Does not apply

What is the process?

- ▶ It involves:
- ▶ Family
- ▶ Individual
- ▶ Health clinicians

Stages

- ▶ Getting the full picture
- ▶ Having a decision to make
- ▶ Being informed
- ▶ Deliberating
- ▶ Understanding the chronic nature of hearing impairment

Thank you

