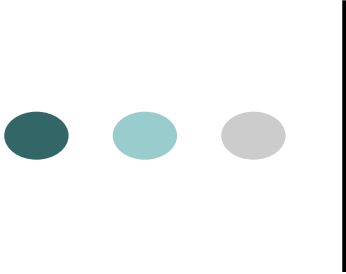


Accessing Treatment and Treatment Adherence





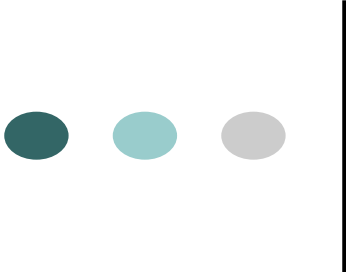
Symptom Perception

- Whether or not we perceive ourselves as having a symptom seems to be influenced by four main sources of information:
 - Bodily data
 - Interaction between internal and external data
 - Mood
 - Stress, depression, anxiety all associated with greater symptom perception (with pre-existing chronic condition)
 - Cognitions
 - Social context

Social context - not always accurate...

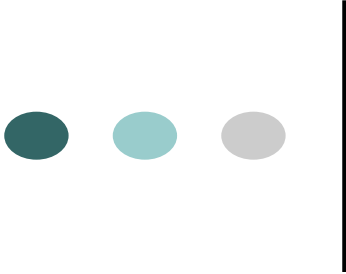
- Medical students' disease
 - Studying symptoms leads to greater focus on one's own symptoms (e.g., of fatigue) that then get interpreted as indicative of disease.
- Mass Psychogenic Illness
 - Widespread symptom perception among a large group of individuals, without any evidence for physical or environmental cause.
 - Factors contributing to this effect are:
 - Cognitive exaggeration of common symptoms
 - Modeling
 - Emotional distress (e.g., anxiety)





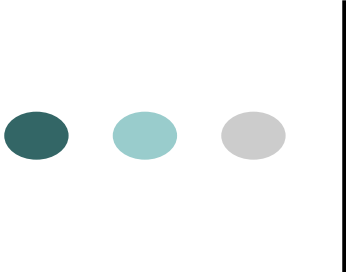
Social Triggers

- Illness cognitions (read Ch 9) – mental representation of the problem
 - Self-regulatory model of illness (Leventhal) links to Lazarus' coping work
 - The **SRMI** theory suggests individuals search to understand illness or disease threat by developing understanding of what illness is, what it means, its causes, its consequences, how long it will last, & whether it can be cured or controlled.
 - This understanding (or illness representation) is not necessarily scientifically or medically validated, but formulated from personal experience (physical symptoms and emotions), social influences, and/or interaction with healthcare providers.
 - Individuals thought to reduce health risk or change health behavior in ways consistent with own illness representation.



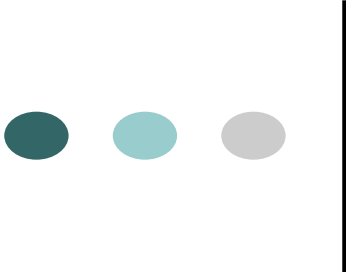
Social Triggers

- Zola (1973) – pathways to the doctor
 - Disturbance in daily life – help seeking to restore equilibrium
 - Interference with work/physical activity
 - Interference with social relations
 - Interpersonal crisis
 - Sanctioning by other people



Lay Referral Systems

- Friends, relatives and co-workers (the internet) form a lay referral system which aids in interpretations of symptoms.
 - Australian adolescents are more likely to seek advice for a health problem from parents and peers before seeing the family doctor
 - I expect there's now abundant 'googling' of symptoms
- People construct common sense models of different illnesses, involving illness identity, causes and underlying pathology, timeline, and consequences



Costs/Benefits of visiting doctor

- Therapeutic

- Effective treatments, specialists
- Don't like being medicated, being poked and prodded

- Practical

- Busy, costs

- Emotional

- Pros and cons – sympathy, company, embarrassment, insecurity

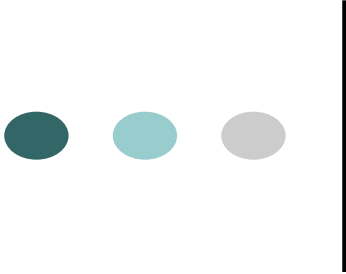
- Sick role

- Absolved from day-to-day responsibilities, but co-operate (adhere) and get better

Delay...

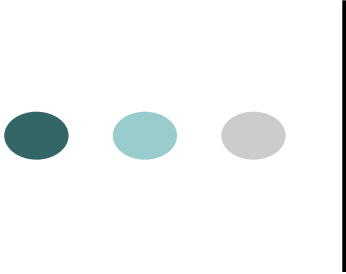
- Time between first detection of symptom and first contact with a health professional.
 - Symptom perception
 - Distraction, overall QoL good
 - Illness cognitions
 - “It’ll go away”, “just ate/drank too much”
 - Social triggers
 - Social network suggests ‘normal’, others not noticing, family has history of xx, that’ll be what it is
 - Costs and benefits of visit to GP
 - Problem minor, don’t want to bother Dr, time/money and inconvenience, not happy with my (any) Dr





Screening

- Some have argued screening is a mechanism of social control (Illich, 1974; Zola, 1973) – medicine taking over people's lives, everyone at risk (healthy perceived as potentially ill), intrusion into people's lives, absolves personal responsibility for health
- More likely to attend screening if:
 - Higher SES
 - Older
 - Healthy...



Medical benefits, psychological impacts

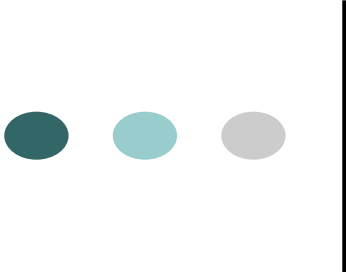
- Obviously – but some questions over approach to treatment (medication vs lifestyle change), issues with invasive treatments that might not confer benefits relative to personal costs
- Screening info – raise anxiety?
- Negative results – generally relieves anxiety, but some want further reassurance
- Positive results – anxiety, shock, fear, etc
- Unclear results...anxiety, concern etc

Why People Don't Use Health Services

- Not trusting practitioners
 - Worry about confidentiality
 - Worry about discriminatory practices
 - Worry about competence



"Your medical records are safe with us. We take patient privacy very seriously."



Why People Don't Use Health Services

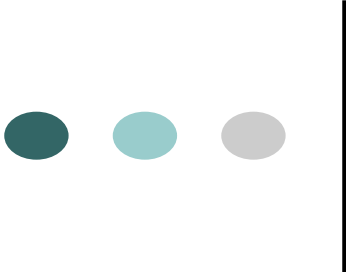
- Emotional factors:
 - fear of serious disease
 - embarrassment
- Social factors
 - Not wanting to appear weak
 - More likely to use health care system if lay referral system encourages it
- Cost

Why People Don't Use Health Services

- Iatrogenic conditions: medical problems resulting from a practitioner's error or as a normal side effect of treatment.
 - Condition is a byproduct of diagnosis or treatment
- Not sure it's a 'front and centre' reason for avoiding, but there are horror stories, and people have access to these, and they can be very emotive
 - A convenient excuse?



Trust Me, I'm a Doctor



“Jumbo Jets Crashing”

- “when extrapolated to the over 33.6 million admissions to U.S. hospitals in 1997, the results of the study in Colorado and Utah imply that at least 44,000 Americans die each year as a result of medical errors³. The results of the New York study suggest the number may be as high as 98,000⁴. Even given the lower estimate, deaths due to medical error exceed the number attributable to the 8th leading cause of death⁵. **More people die in a given year as a result of medical errors than from motor vehicle accidents (43,458), breast cancer (42,297), or AIDS (16,516) ⁶.**”

- ***To err is human: Building a safer health system 1999 – raised awareness***

- ***“the iatrogenic death rate is equal to about three loaded jumbo jets crashing and killing everyone aboard every two days!”***

- (*Journal of the American Medical Association*, July 5, 1995, 274:29-34).

- According to the Australian Department of Health eight per cent of hospital patients are injured or die due to doctor or hospital errors. A study conducted jointly by the Adelaide and Newcastle universities examined admissions at 28 South Australian and New South Wales hospitals.

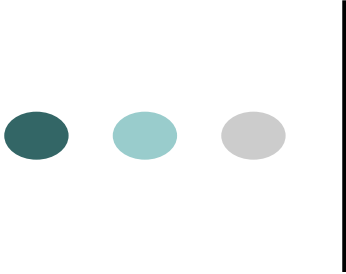
- ***The study found that the medical profession is the third leading cause of death in Australia.***

Iatrogenic Events - NZ

Country in which the study was done	No of records studied	Adverse events % of admissions	Permanent harm and death % of admissions
Australia ⁵	14,179	16.6	2.3
America ⁶	30, 195	3.7	
America ⁷	14,565	10.0	2.0
Canada ⁸	3,745	7.5	1.6
Denmark ⁹	1,097	9.0	0.4
England ¹⁰	1,014	11.7	1.5
New Zealand ¹	6,579	12.9	1.9

Merry, Seddon et al., 2006

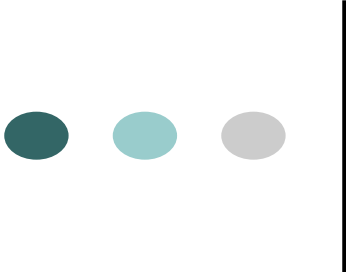
Same as elsewhere...



The Patient/Practitioner Relationship

- People differ in the role they want to play in their treatment
- **Patients who take an active role recover better and faster**
- Practitioners differ in the level of participation they are willing to allow

	Physician Control	
	Low	High
Patient Control		
Low	Default	Paternalistic
High	Consumerist	Mutuality



What Happens When There is a Mismatch?

- Although physicians and patients agree that patients should play a role, neither tends to act this way.
- If the patient wants to participate and the practitioner doesn't want them to, conflict will result.
- If the practitioner wants the patient involvement but the patient doesn't want to participate both are uncomfortable.

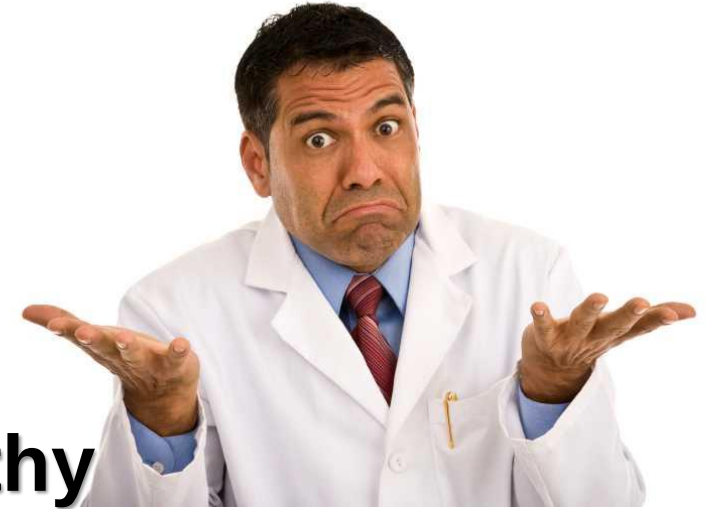
The Practitioner's Behaviour

- Physicians tend to use a consistent style.
- Two general styles:
- Doctor-centred
 - Asks closed-ended questions and focuses on first problem mentioned.
 - Ignores attempts to discuss other problems
 - Paternalistic
- Patient-centred (less common)
 - Asks open-ended questions and allows discussion
 - Avoids jargon and encourages participation in decisions



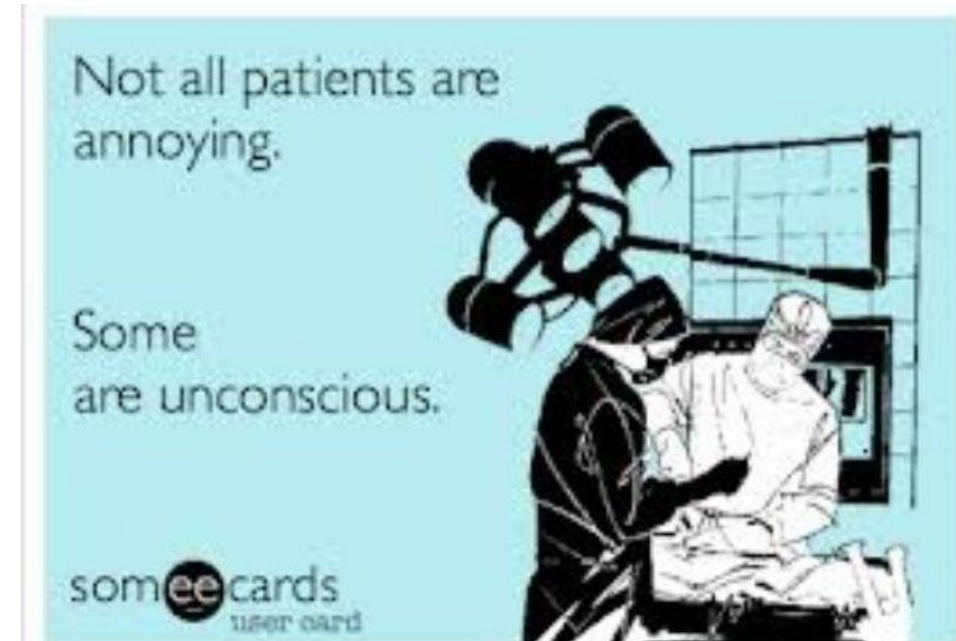
What do we want in a doctor?

- **Competence**
- **Expertise**
- **Concern, warmth, sensitivity, empathy etc**
- How do “good” doctors benefit?
 - Patients seem to adhere to treatment
 - Obtain more extensive (biopsychosocial?) diagnostic information



The Patient's Behaviour that Upsets the Doctor

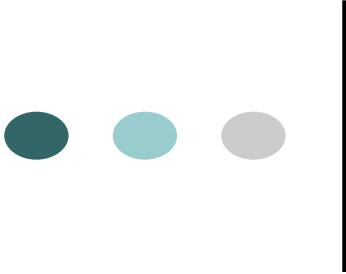
- Expressing anger or criticism
- Ignoring or not listening
- Insisting on procedures the physician thinks are not necessary
- Requesting the doctor certify something he/she does not think is true (e.g., disability)
- Sexually suggestive remarks



How do patients impair communication?

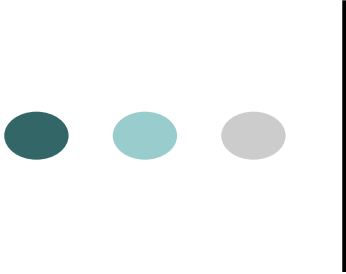
- Not indicating distress
- Indicating too much distress
- Poor communication of symptoms





Terminology – compliance & adherence

- Compliance
 - “extent to which the patient’s behaviour matches the *prescriber’s* recommendations”
 - Implies lack of patient involvement
- Adherence
 - “extent to which patient’s behaviour matches *agreed* recommendations from the provider”
 - The extent to which the patient’s behaviour coincides with medical advice in terms of taking medications, lifestyle changes, and future appointments
 - **Emphasises need for agreement**
 - **Emphasises freedom of patient**

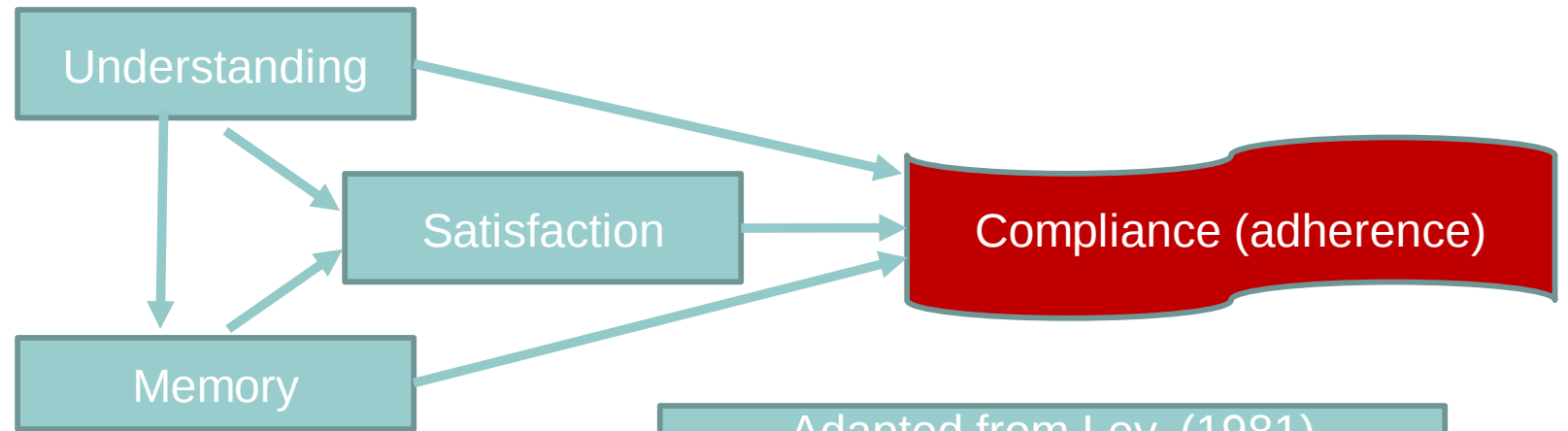


Non-adherence

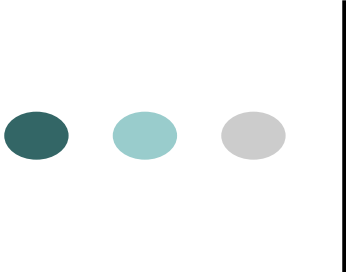
- Not following advice given by (agreement with) healthcare professionals
- Variable behaviour, not a trait characteristic
 - Most people are non-adherent some of the time
- Unintentional non-adherence
 - Passive non-adherence
 - Caused by barriers such as forgetting, inability to follow instructions, lack of understanding, or physical problems e.g., poor eyesight
- Intentional non-adherence
 - Active non-adherence
 - Patient decides not to take treatment as instructed
 - Arises from beliefs, attitudes and expectations

Predictors

- Patient satisfaction
- Patient understanding
- Patient recall
- Beliefs about illness
- Beliefs about medication

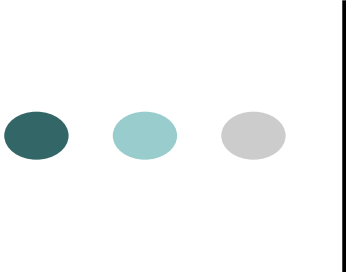


Adapted from Ley, (1981)



Dangers of non-adherence

- The patient fails to get better
- The patient may get worse
- Misdiagnosis
- Resistant organisms
- Poly-pharmacy (concurrent use of multiple medications)
 - 10-20% of patients have an unnecessary prescription
- 5-10% further doctor visit
- 5-10% extra 1-2 days off work
- 0.25-1% 1-3 days in hospital



Factors influencing patient recall

- Medical jargon
- Importance
 - Statements perceived as important recalled better
- Primacy effect
 - Material presented first is better recalled
 - Diagnostic advice remembered better than treatment advice
- Unclear instructions
- Low levels of information

Why Physicians Use Jargon

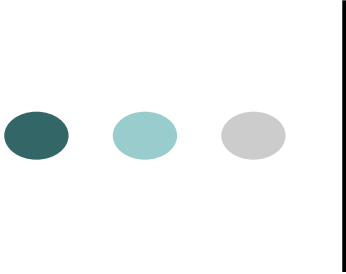
- Habit
- Patient doesn't need to know
- Patient better off not knowing
- Keep interactions short
- Reduce emotional reactions
- Reduce recognition of errors
- Elevate practitioner's status
- Not aware of jargon

MEDICAL NOTES DECODED

UBI Unexplained Beer Injury	FLK Funny-Looking Kid	NFN Normal for Norfolk
TUBE Totally Unnecessary Breast Examination	GPO Good for Parts Only	GLM Good-Looking Mum
TFTB Too Fat to Breathe	TEETH Tried Everything Else, Try Homeopathy	NQR Not Quite Right
LOBNH Lights on but nobody home	PAFO P****d and fell over	CTD Circling the Drain
DBI Dirtbag Index - number of tatoos multiplied by number of missing teeth as an estimate of the total number of days patient has gone without a bath	GOK God Only Knows	TLR Two-Legged Rat - refers to a patient undergoing experimental or extreme treatment

SLANG AND PSEUDONYMS

FREUD SQUAD Psychiatry department	GASSER Anaesthetist	SLASHER Surgeon
BABY CATCHER Obstetrician	REAR ADMIRAL Proctologist	CHEER IOMA A tumor from which the patient will not survive
RULE OF FIVE If more than five of the patient's orifices are obscured by tubing, he has no chance	FOREVERECTOMY A surgical procedure that lasts a very long time	



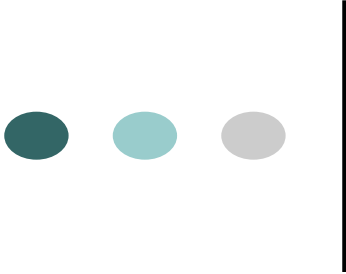
Improving patient recall

- Important information first
- Stress importance
 - “It’s very important that you remember what I am going to say next...”
- Simplification
- Categorisation
 - “Now I’m going to tell you what’s wrong with you/what the treatment will be/how to take your medication...”
- Repetition
- Specific, concrete statements
 - “Go for an hour’s walk, 3 times a week” vs “Exercise regularly”
- Written information
- Check for understanding

Beliefs about medicines

- Dual nature of medicines – healing and harm
- Judging efficacy – symptom control and side effects
- Negative concerns
 - Dependence
 - Continual use
 - Chemical vs natural
 - Overuse





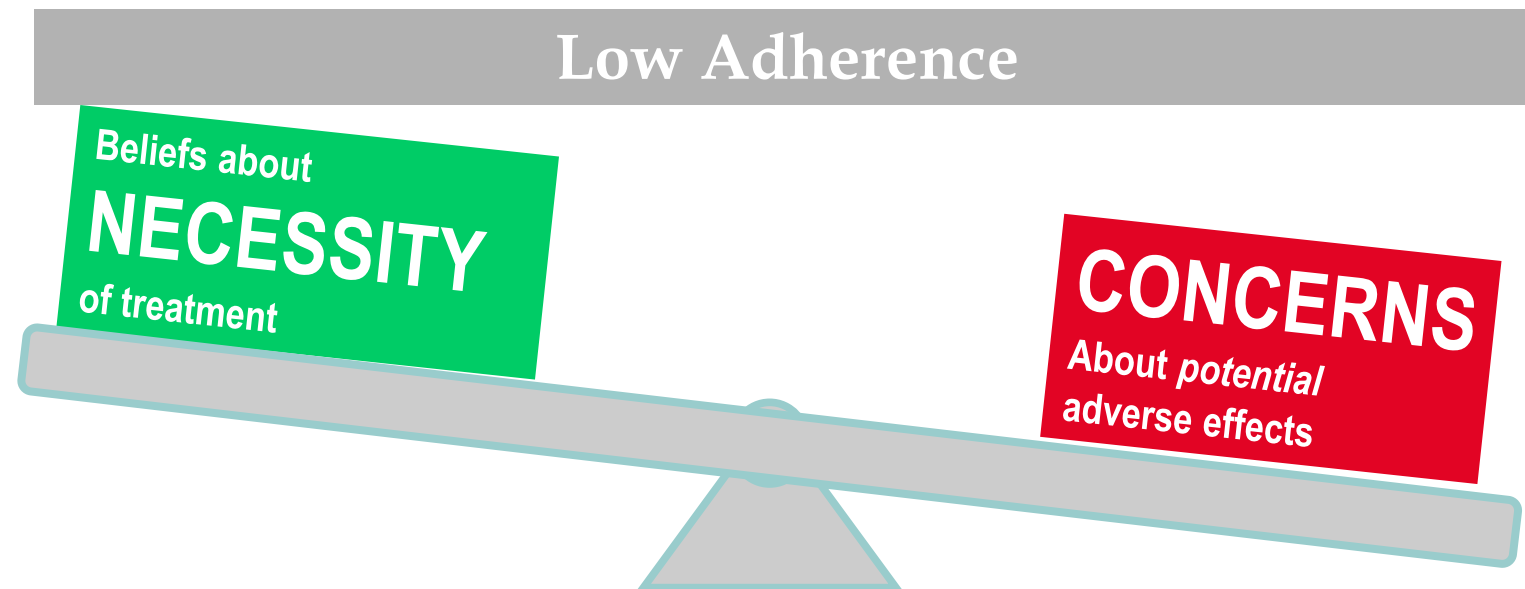
Measuring beliefs about medicines

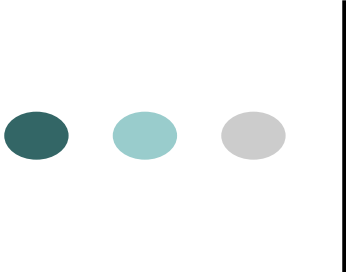
- Beliefs about Medicines Questionnaire (BMQ) (Horne, Hankins & Weinman, 1999)
- Assesses mental representations of medications
- BMQ-General – pharmaceuticals as a treatment generally
 - Harm
 - Overuse
- BMQ-Specific – specific to meds prescribe for an illness
 - Necessity (for maintaining health)
 - Concerns (over potential negative effects)

The Necessity–Concerns Framework

(Horne, 1997, 2003, 2006)

Studies across range of illnesses, countries and cultures indicate that the Necessity–Concerns framework is useful for explaining/understanding low adherence



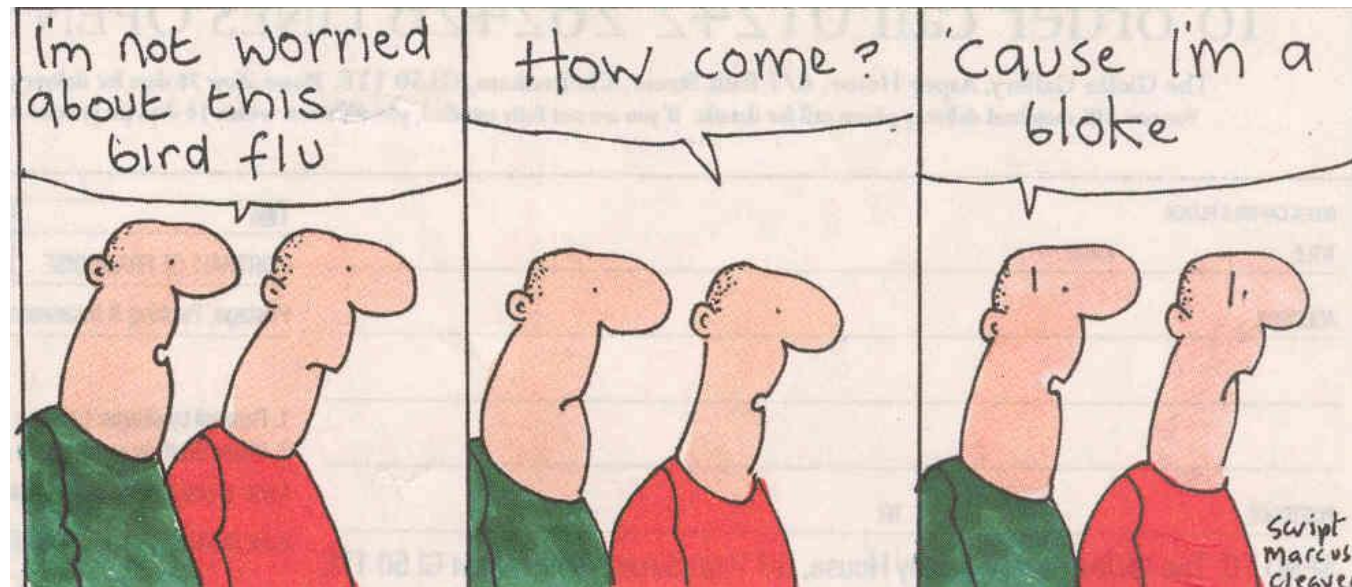


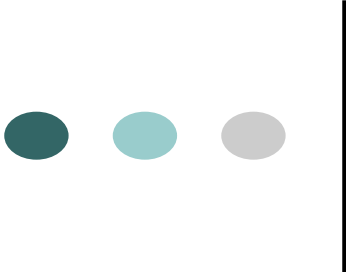
Perceptions & Practicalities Approach for facilitating informed adherence to medication Horne (2003)

- Provide a rationale for personal **NECESSITY**
 - consistent with patients' 'common-sense' model of the illness – initiation and maintenance
- Elicit and address individual **CONCERNS**
- Tailor a convenient regimen that fits patient's lifestyle and preferences, and addresses practical barriers

Coherence

- Need for 'common-sense coherence' between representations of illness and treatment





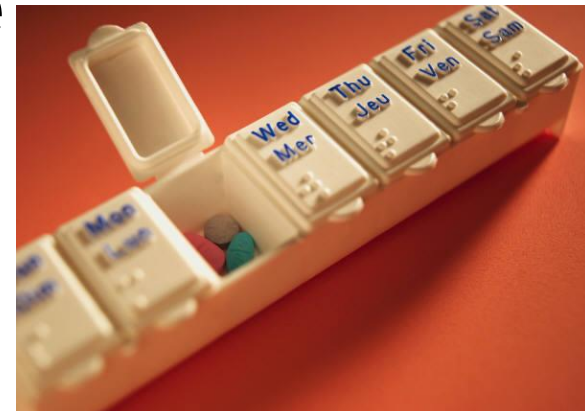
Coherence

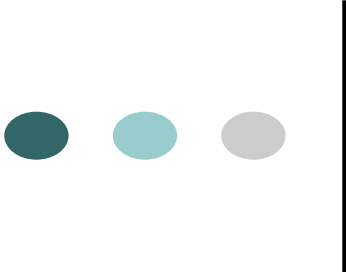


- e.g., asthma
 - Medical model of asthma as a chronic condition requiring daily maintenance treatment
- vs**
- Patient experience of asthma as an episodic condition - symptoms come and go
 - No symptoms = no asthma (Halm et al., 2006)
 - Patients with this model had stronger doubts about personal need for inhaled corticosteroids and lower adherence (Horne & Weinman, 2002)

Improving adherence

- Relationship – satisfaction
- Discussion, time, understanding
- Reduce number of medications where possible
- Use longer acting medications to reduce number of times taken during the day
- Use calendar dispensers where possible
- Co-ordinate timing of doses





Summary...

- Many interventions, many reviews
- Haynes et al., (2002) – Cochrane systematic review
 - “*complex strategies for improving adherence to long-term medication prescriptions are not very effective despite the amount of effort and resources they consume*” (p. 9)
- Even successful interventions have modest or short-lived effects.
- Most focus on *unintentional* non-adherence, with implicit assumption that effective communication and patient education are the key
 - But much non-adherence is intentional, and almost all is likely to have multiple determinants