

PATIENTS' EXPERIENCE OF LIVING WITH FAECAL INCONTINENCE:

**INITIAL STUDY &
5 YEAR FOLLOW-UP**

Mary Wilson
Advanced Practitioner: Bladder & Bowel Health

Initial research

- 22 community dwelling adults
- Interviews 2.4.02 – 16.9.03
- Aim: to find out what it is like to live with faecal incontinence (FI)

Imagine that **you** had lost bowel control in a **public place**.
What would pass through your mind?

Neither your **home** nor your **car** is nearby.

?

WHAT ON
EARTH SHALL I
DO???

it's like a bad
dream, but I'm
not asleep

I don't know
where the
toilets are

does anyone
round here
know me?

can anyone
smell
me?

I don't want to
cause
unpleasantness
for others

it's come
through my
trousers

I'm panicking -
I WANT TO CRY.
I wish my partner
was here



Imagine - -

- You have been faecally incontinent
- You are in town and have no spare clothes
- It is too far to walk home

What would you do?



?? Take a taxi

*NO – too confined
a space*

?? Take a 'little bus'

*YES – & sit at the
back*

"It filled up obviously as we went along.

*I walked from the back and I thought
'oh - all those people sat with me bum
literally level with their faces'.*

*And when I got in, I just howled -
and you can't explain that to anybody"*

(♀ 48, initial study, obstetric, IBS & other
chronic conditions)

The Result

- Feeling stigmatised
- . . . And socially unacceptable
- . . . And alone . . .

“I don’t know anyone else it happens to”


“There’s no-one I can talk to about it”

- Can become reclusive
- Reliant on close family members

RESEARCH METHODS

- Grounded theory
- In-depth guided interviews
- Coded transcripts
- Constant comparative method
- 'Framework' analysis

INDEPENDENT THEMES

- Self esteem, self-confidence, feelings of control
- Response, adaptation, responsibility
- Interaction with significant others, and the generalised other
- Life direction 
- Interaction with HCPs

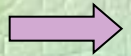
CATEGORIES

- **Overwhelmed**

-ve expression of themes



- **Accommodating to FI**



- **Approaching Mastery**

+ve expression of themes

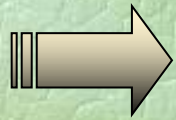




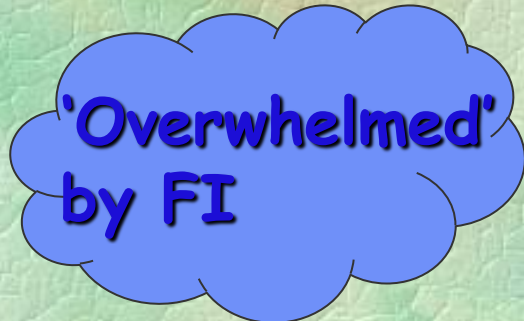
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A D-Y-N-A-M-I-C CONTINUUM



'OVERWHELMED' by FI

- Often early in trajectory - 'black days'
- Look back to 'golden past'
- Lack of confidence
- Low mood → effect on relationships
- Reactive management
- Reclusive - ↓ risk of FI
- Feeling stigmatised
- Looking for role model
 - as long as comparable in features

'ACCOMMODATING to FI'

- May have been overwhelmed in past
- Accepting and stoical resignation
- Guided by HCP
 - and waiting in limbo for help
- Acceptance of/comfortable in 'sick' role
- Lifestyle modification - ↓ risk of FI
- Unlikely to discuss FI outside private domain

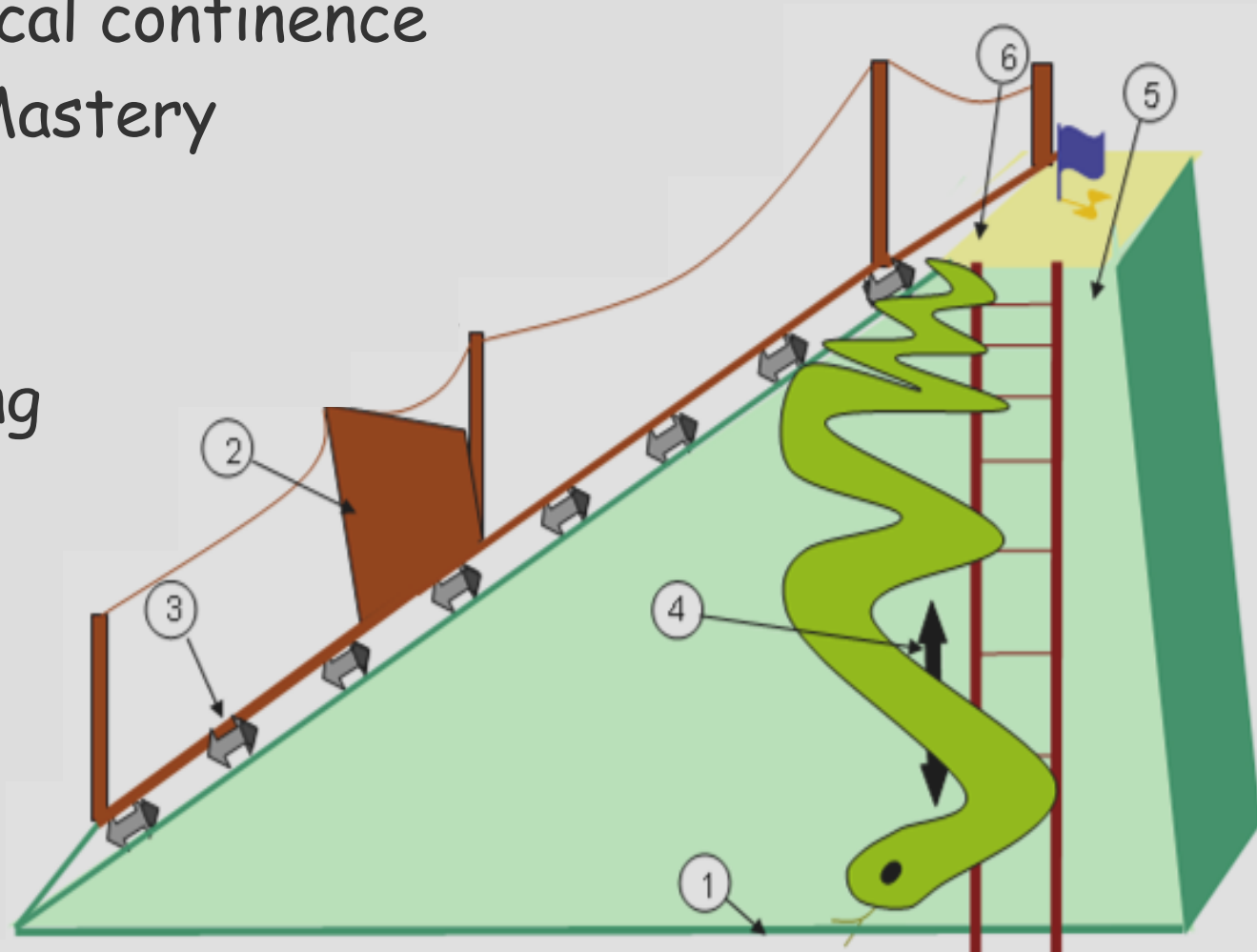
'APPROACHING MASTERY'

along the D-Y-N-A-M-I-C continuum

- May have had FI for a long time
- May look back to being overwhelmed
- Pro-active management - trial & error
- But listening to the body
- May talk openly about FI
- Progressive narrative

The escarpment

- ⑥ Plateau of faecal continence
- ⑤ Approaching Mastery
- ④ Steep slope
- ③ Gentle slope
- ② Accommodating
- ① Overwhelmed



5 YEAR FOLLOW-UP

- 11 community dwelling adults
 - half the original sample
 - still characteristic of original sample regarding variables e.g. gender, condition
 - BUT
 - average age > 5yrs older than initial study
 - greater proportion of volunteers
- 9 were 'Approaching Mastery'
 - of which 1 had been 'Overwhelmed'
- 1 was 'Overwhelmed', now 'Accommodating' to FI
- 1 was still 'Overwhelmed'

The other 11?

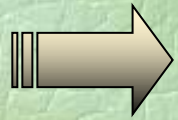
- 4 had passed away (2 x 'Overwhelmed', 2x 'Accommodating' to FI)
- 1 had moved away for career reasons ('Approaching Mastery')
- 3 chose not to re-join: one from each group ('O', 'Acc' to FI & 'AM')
- 2 were not well enough ('Approaching Mastery' & 'Accommodating' to FI)
- 1 did not qualify
 - The Newcastle man who piloted topic guide ('Accommodating' to FI)

5 YEAR FOLLOW-UP

- Interviews 14.12.07 - 21.1.09
- Aim: to find out how they have got on
- *I'd spent so much time analysing their transcripts that it was like reuniting with old friends!*

The majority of the sample

- *had progressed along the*



D-Y-N-A-M-I-C CONTINUUM

- had gone round the world
- or enjoyed a week long coach holiday
- able to act as a role model for someone less advanced in adaptation



As they 'Approached Mastery'

'Accommodating' to FI (n=1)

- **Previously 'Overwhelmed'**
 - got mixed messages from HCPs and did not know who to believe
 - unhappy with stoma
- **Now in a comfort zone but is content**
 - 'taking a 'breather'
 - now no stoma - requested that it was closed
- **Anticipating being able to do more**
 - deriving satisfaction from helping someone comparable but worse off

'Overwhelmed' by FI (n=1)

- Reasons why there had been little movement along the continuum were:
 - FI had become more severe
 - other chronic illnesses or the treatment for them had affected bowel control
 - lack of confidence in / reluctance to try pro-active trial and error
- Resulted in dwelling on -ve aspects of life, reactive coping and frustration as a result of downgrading previous goals

Why did people vary in their ability to move along the continuum?

Do people vary?

- relevant traits that can help?

Does it relate to their (bowel) condition?

Remember the **INDEPENDENT THEMES**

. . . from the initial study?

- Self esteem, self-confidence, feelings of control
- Response, adaptation, responsibility
- Interaction with significant others, and the generalised other
- Life direction
- Interaction with HCPs

Friborg, Hjemdal et al., 2003)		Dimensions: RESILIENCE SCALE FOR ADULTS (RSA)	Description of what the dimension measured
Categories of resilience	Dispositional attitudes	Personal competence	Self-esteem, self-efficacy, self-liking, hope, determination and a realistic orientation to life
		Social competence	Extraversion, social adeptness, cheerful mood, an ability to initiate activities, good communication skills and flexibility in social matters
		Personal structure	The ability to uphold daily routines, to plan and organise
	Family coherence/ warmth	Family coherence	Family conflict, cooperation, support, loyalty and stability
	External support systems	Social support	Access to external support from friends and relatives, intimacy, and the individual's ability to provide support

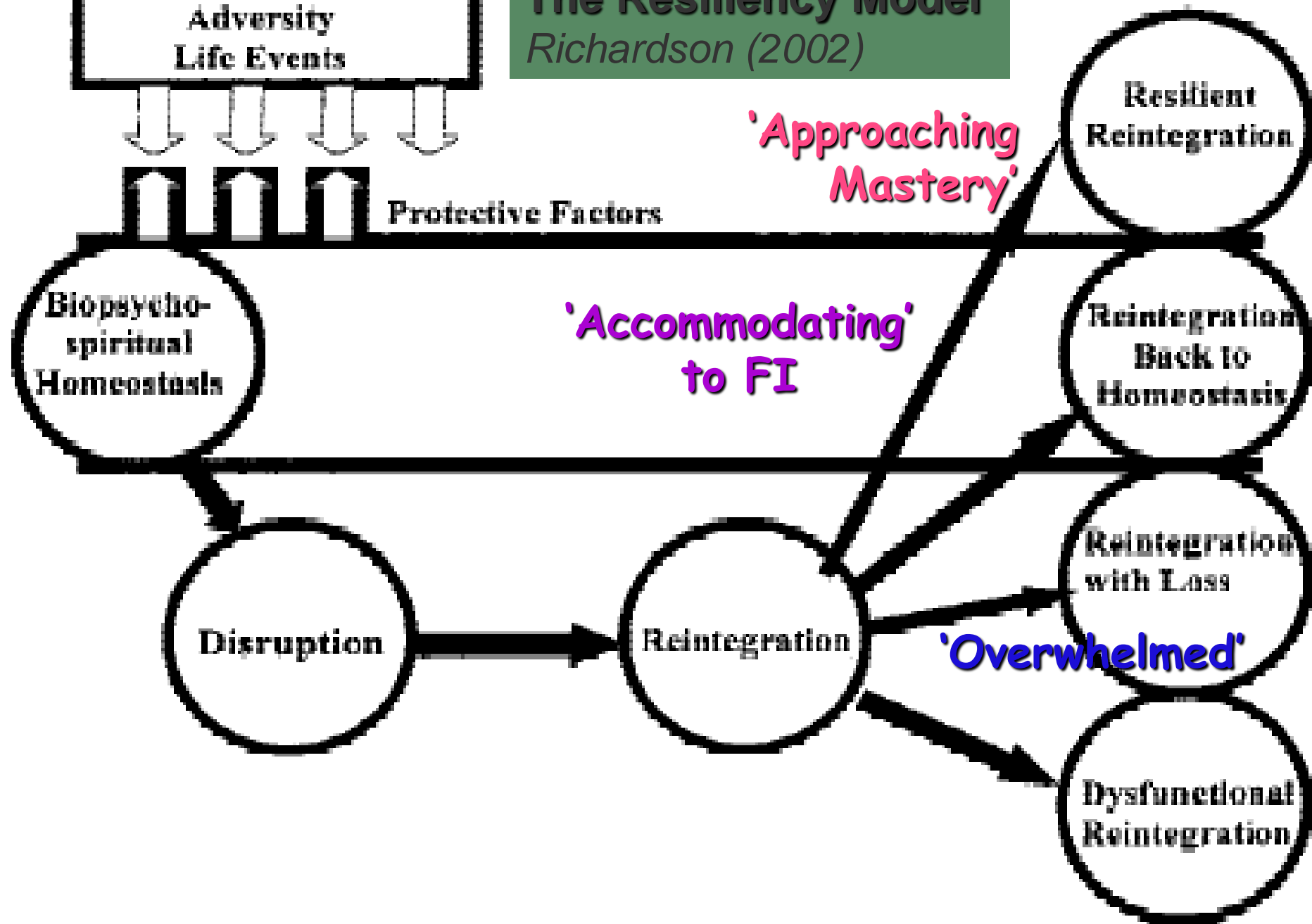
Resilience: 2 ways of interpretation

- Either the traits that help people to adapt
 - i.e. 'bounce back-ability' to disruption
(e.g. Friborg et al. 2003)
- Or the **outcome** of a disruption in life like developing faecal incontinence (Richardson 2002)
 - THE OUTCOME MAY VARY (-ve to +ve)
 - (like the dynamic continuum??)
 - resilience can be learned/developed through experience
 - but is not automatically transferable between experiences
 - but ?? easier when these traits are present
 - Richardson (2002) calls them 'protective factors'
(↔ Friborg et al. (2003) 'dispositional attitudes')

Stressors
Adversity
Life Events

The Resiliency Model

Richardson (2002)



Self regulation (*Brandstädter*)

- Assimilation: tenacious goal pursuit (TGP)
 - more often in younger/middle aged
 - 1ry cycle of compensation: *learning new skills*
 - 2ry level of compensation: *to allow TGP to continue*
 - compensatory measures: *external means delaying FGA*
 - OR . . . *external means to assist return to TGP*
- Accommodation: flexible goal adjustment (FGA)
 - downgrading aspirations as a result of normal aging or more severe disability
 - older people - drop in dopaminergic neuromodulation decreases appetite for TGP

What external means?

- Means to reveal the severity of FI
 - e.g. loperamide
- Means to enable the person to manageable



The holder of this card has a medical condition which requires the urgent use of a toilet



Other factors help/hinder?

Significant others

- A partner with whom relationship is good
 - acceptance, warmth, understanding
 - emotional support - buffer effect on stress
 - more effective than parents/children/siblings
- But if the relationship is poor, -ve interactions more potent on wellbeing than +ve ones

I says [to wife] 'I don't know about a [stoma] bag, I could do with a bucket'.

That's all I said, I said 'I'd be better with a bucket, strap a bucket round my neck'.

And she couldn't eat 'er tea, so naturally, I don't talk to 'er [about it] ... I thought I was normalising. You've got to get used to it, I suppose. But I feel a bit 'elpless. An' I think, 'why 'ave I to do it on my own?'

(♂ 64yrs, initial study, Crohn's, 'Overwhelmed' ... but 'Accommodating to FI at Follow-up)

[Partner] *understands. Yes. I mean, he knows how distressed I am. He's very good. 'Cos I say 'oh I need to go to the loo' and he flies out . . .*

Yes, I mean he is very, very good, you know, and if he can do anything to help me he would.

(♀ 60, initial study, obstetric, IBS? 'Overwhelmed' . . . but was 'Approaching Mastery' by follow-up)

Role Models

When 'Overwhelmed' – need to be similar in every aspect that is felt important by the individual:

"I got a message from the girl I was in hospital with. She got a lot of the same symptoms as I did. And she's just had a colostomy put on. And she said 'oh if you have to have one done, don't worry, it's not as bad as you think it's gonna be'. But, you see, she's in a happy marriage. She's been married for nearly thirty years or something, and it's a different situation"

(♀ 38, initial study, partial colectomy)

Recommendations for practice

- It may be that the individual requires different interventions at different stages of the continuum
 - and if s/he has different social support
- Assist with external means appropriate to client's goals
 - therapeutic, pharmacological, practical
- If 'Overwhelmed' ? would a role model help?
 - or if 'Approaching Mastery' could s/he help another individual?

