

Behaviour that Challenges Us: From Symptoms to Stories

Dr Graham Stokes

Divisional Director of Dementia Care, Bupa Care Services

Bupa Care Homes



What is a behaviour that challenges?

- That's not complicated
- It's a behaviour that someone cannot cope with, for if they could cope they wouldn't be challenged.

Behaviour that challenges us

A challenging behaviour is an act of severity, as measured by intensity, frequency or duration, that either places the physical safety or psychological health of the person or others at risk, or limits the person's access to normal lifestyle opportunities thereby resulting in social exclusion.

The nature of behaviour that challenges

- Acts of omission (**dependency**) are historically and typically well tolerated - with the probable exception of disengagement (an absence of behaviour)
- Acts of commission are typically experienced as challenging

Diagnostic overshadowing

Personhood

- The greatest transformational change in dementia care is embraced by the word – **person**.
- People living with dementia.
- I wrote in 1995 it's “*person first, dementia second*”.

Mrs S

We remain who we are

- Women who hover to avoid making contact with the toilet seat - **72.6%** sometimes or always.
- Women who place toilet paper on the seat before sitting on it - **60.8%**
- Women who wipe round the toilet seat prior to using it - **83.6%**
- Women who avoid touching the flush handle by using, e.g. paper or another part of their anatomy - **56.1%**
- Women who on leaving the toilet avoid touching the door handle – **47.3%**

Limitations of the Pathology-Centred Model (i)

- **Inter-individual variability** - Not all people with dementia present with behaviour that is challenging, and those that do often present with specific challenges that are context - and sometimes time - bound challenges.

The consequences of terminology

- Non-cognitive **symptoms** of dementia
- **Behavioural and Psychological Symptoms of Dementia** (Finkel, 2000)
- Contributes to the excess prescribing of antipsychotics (Banerjee, 2009)

That which people with dementia share in common you can attribute to the disease, that which they do not share in common you can rarely attribute to the disease

Limitations of the Pathology-Centred Model (ii)

- **Weak correlation with post-mortem data**
- **Catastrophic decline**
- **Resolution (rementia)**

Acts of commission are associated with:

- family carer strain - **why ?**
- referral to mental health teams
- treatment with antipsychotic drugs
- request for respite care
- collapse of care at home
- hospitalisation for assessment and management
- entry to a care home

= a health economic challenge

Carer burden and strain

- Skills deficiency
- The burden is felt as endless
 - Aggressive outbursts are better tolerated than repetitive questions.
- Overwhelming sense of loss - of person and relationship

There is synergy between the two approaches.

- Pathology-centred model is diagnostic
- Dementia is conceptualised as an intellectual disability
- Person first, dementia second – how does a person with dementia survive, how do they communicate their needs?
- Behaviour that challenges us – reflects the needs of people living with dementia, not symptoms to be managed.

Person First Coalesces Around the Individual and their Setting

- A person who is unique
- Yet with whom we share more in common than what separates us
- Enduring a world of not knowing, resonating with threat, mystery and insecurity - a world that we can barely comprehend.

Functional Analysis - Mr. G: a man to be known

- 2 week baseline period - **47** violent episodes
- Behavioural (ABC) analysis revealed 95% of assaults were against care staff
- 89% of incidents related to toileting
- Severe dementia (MMSE score - 7:30)
- Toilets located in corridors. Limited visual access. Environment not legible.

(Stokes 2008)

Functional Analysis - Mr. G: a man to be known. Who is he?

- Retired teacher
- Taciturn
- Humourless
- Introverted
- Ill at ease in company
- Stubborn
- Inflated sense of his own importance
- Passionate gardener

Mr. G: Presenting us with needs to be met, not a problem to be managed

- Functional analysis yields a formulation
- **2 competing sets of needs**
- a need for hygiene - that could only be met with assistance
- a need for privacy and self-respect

Revised Care Plan

- Action plan?
- Outcome: during 2 week post- intervention period

~ 6 episodes of violence

Jane: A toilet ‘crawling with worms’

- **Challenge: Toilet refusal with accompanying aggressive resistance**
- **incontinence pads rejected**
- **neuropsychological assessment = perceptual disturbance (i.e. agnosia)**
- **toilet floors - black and white floor tiles**
- **person variable**

Fear of worms



(Moniz-Cook, Stokes and Agar, 2003)

Revised care plan: function, formulation and intervention

- **Function:** Behaviour is a flight-fight response when confronted with an anxiety provoking stimulus
- **Formulation:** Agnosia is resulting in misperception of black and white tiles. Seen as black lines on a white background. Lines misinterpreted by Jane as worms. The outcome is dread, anxiety and if care action persists, panic and resistance.
- **Primary causation: Fear of worms**
- **Secondary causation: Role of dementia - impairment of memory, communication and reasoning, and agnosia.**
- **Action: Paint toilet floor dark red**
- **Outcome:** Appropriate independent toilet use

Research results

