Distress in residential dementia care

Mike Bird

Bangor University

and

Aged Care Evaluation Unit, Greater Southern Area Health, NSW, Australia

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Plan

- **Case studies**
- **Resident distress**
- **Staff distress**
- **Interventions**

Pauline, 85 years

Causes

- Chronic pain escalating through day
- ‘Busy busy’ pre-morbid personality

Interventions:

Systematic pharmacological and psychosocial pain relief; diversion

Pauline. Intrusive destructive behaviour

Bill: 70

- Blind nursing home resident
- Dementia unspecified overlaid on developmental delay
- Not testable on MMSE; CDR = Severe
- Referred for yelling and public masturbating
- On anti-convulsant, antipsychotics and benzodiazepines

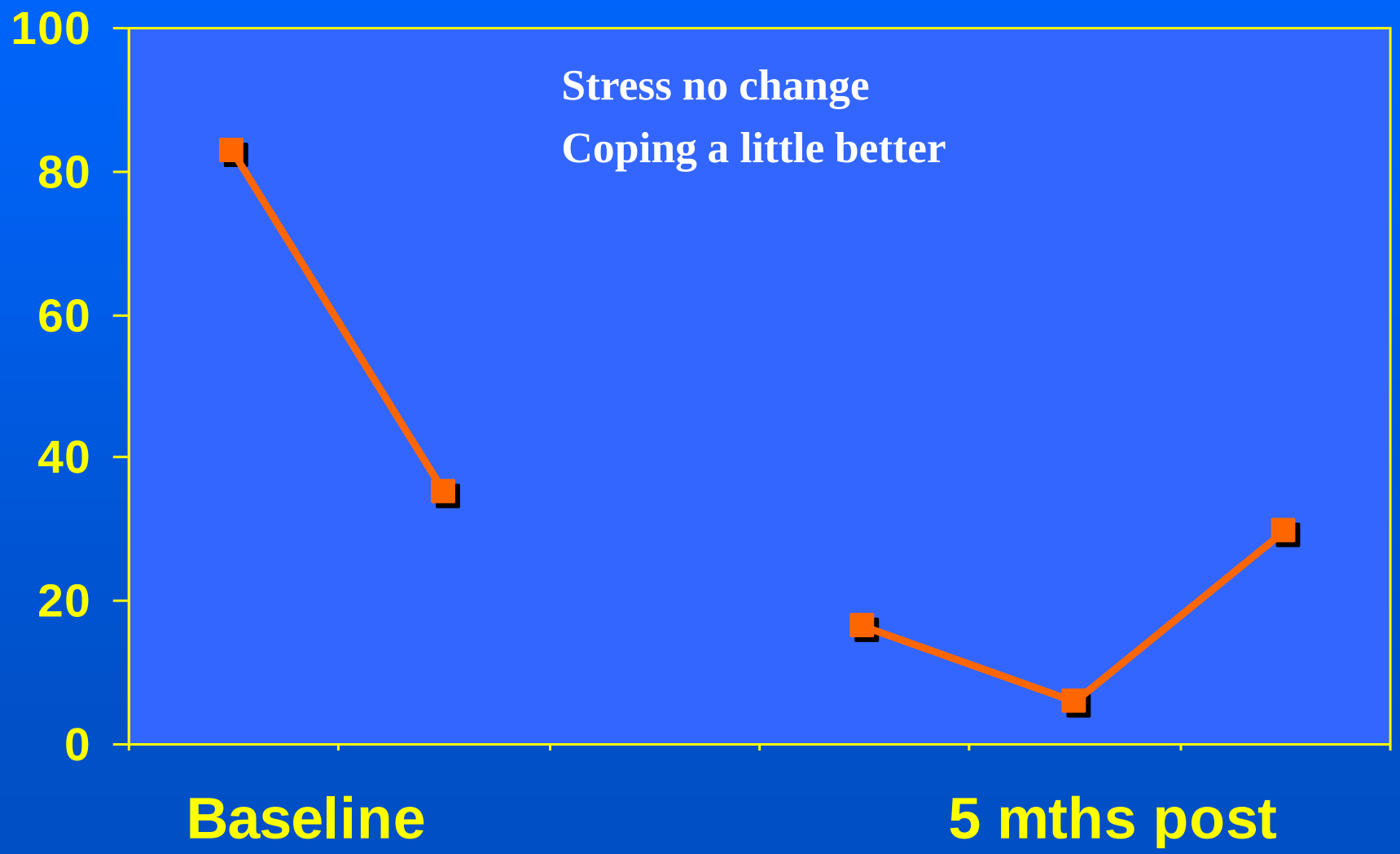
Context

- ***Why aren't I dead? Who am I? Help me!***
- **Frequent crying, no appetite**
- **Almost no social interaction than reprimands**
- **75% of content of yells easily met**
- **In pain and discomfort**

Management

- Cease anti-psychotics, commence anti-depressants
- Accommodate in own room rather than public corridor
- Education for staff on Bill's emotional and physical needs and regular timed visits to meet those needs
- Regular bath before usual yelling start-up time
- Regular pain relief rather than PRN
- Tune bed-side radio to Bill's preferences
- Yelling drops from about 60 per hour to 10 yells
- Reduction in hopeless comments, crying. Some smiling. Appetite improves

Bill: Frequency (per hour) of calling out



Marie 73: Causes of the behaviour

Brain lesions leading to perseveration

Exacerbated to high levels by:

- Chronic UTIs
- Other physical discomforts incl. thirst and pain
- Staff response makes behaviour worse
- Lots of movement in line of sight at busy (especially meal) times
- Waking her at night

Marie: Intervention

Low dose anti-convulsants (only effective limited period)

Regular pain management rather than PRN

Rigorous UTI monitoring and prevention

Staff education on resident's background

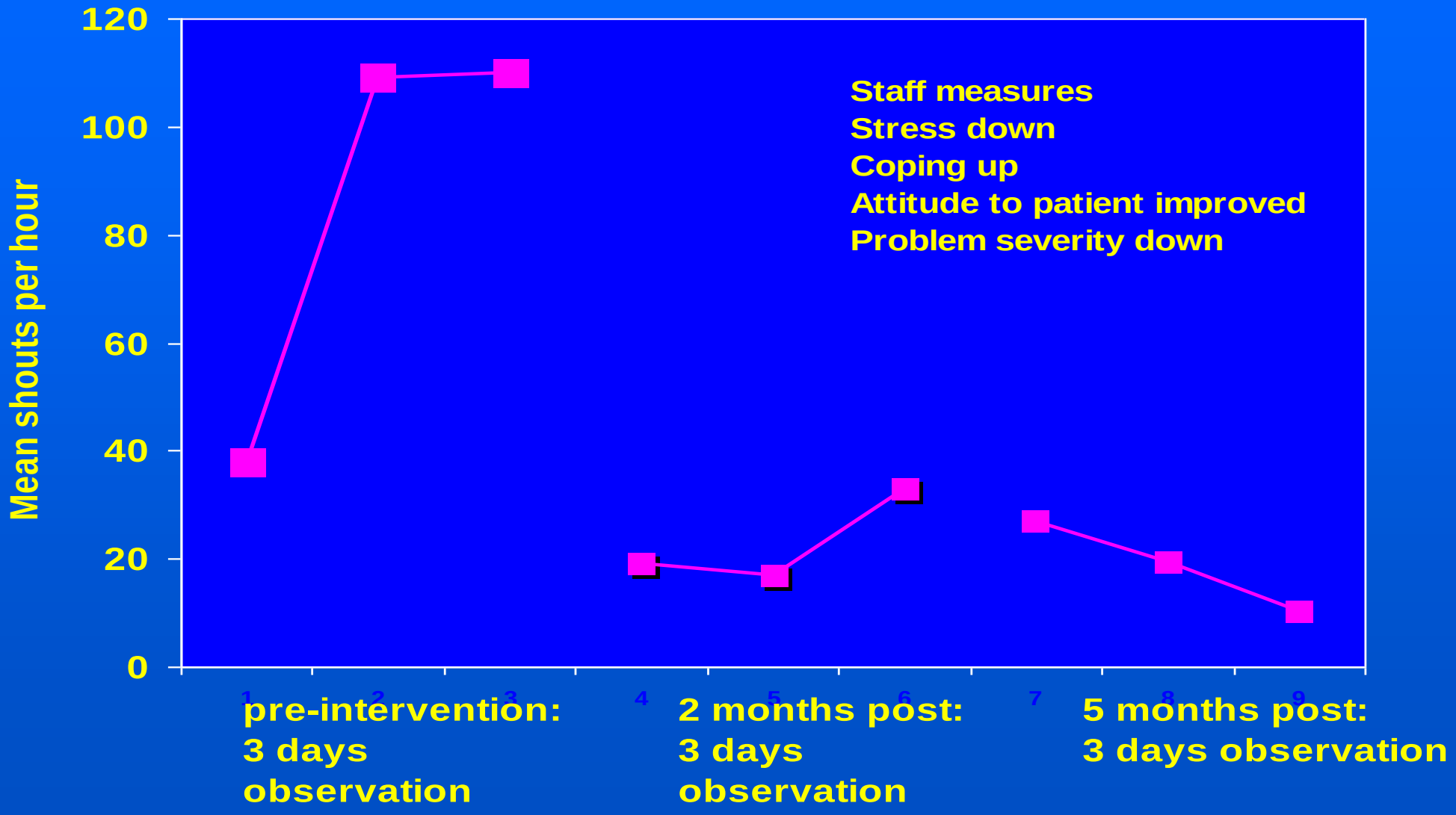
Behavioural experiments with staff:

- **Ignoring her demands but providing care at timed intervals**
- **Taking meals in her rooms**

Not waking her at night and negotiating with day staff that this is OK

Letting her sleep till natural waking time

'Marie'. 73 years: Shouting: Intolerable demands on staff



Main points from case-studies

- **Disturbed behaviour occurs for a reason, and in dementia it is often an expression of suffering**
- The suffering is two-way: care staff are also often in significant distress
- The role of the intervention is to reduce suffering not necessarily to ‘cure the syndrome’.

Common attributions

The behaviour occurs because...

- They have dementia
- Of cerebral irritation
- They are attention seeking
- They are manipulative
- They are naughty

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Commonly reported sources of staff stress

- Resident variables: Impact of behaviour
- Systemic variables.
  - Staff patient ratios
  - N.H. Organisation/Culture
- Within-staff variables:
  - Understanding of dementia
  - Attitude
  - Skills
  - Sense of efficacy
  - Personality

Behaviours	*Rank order*	*Rank order incidents*
Aggression	**1 (29.0%)**	**1 (34.8%)**
Repetition (actions/questions)	**2 (17.1%)**	**9 (0.9%)**
Resistance to care	**3 (8.9%)**	**3 (19.4%)**
Restlessness/anxiety/wandering	**4 (8.2%**	**2 (21.6%)**
Verbal disruption	**5 (6.1%)**	**4 (8.8%)**
Shadowing/constant attention	**6 (5.8%)**	**10 (0.9%)**
Incontinence/toileting problems	**7 (5.5%)**	**7 (2.2%)**
Communication problems/confusion	**8 (4.8%)**	
Disinhibition	**9 (3.8%)**	**6 (3.1%)**
Depression/suicidal/teary/upset	**10 (2.4%)**	**5 (5.3%)**
Risky actions (eg. throwing self on floor)	**11 (1.7%)**	**8 (1.3%)**
Unjustified accusations	**12 (1.4%)**	
Delusions/hallucinations	**13 (1.4%)**	**9 (0.9%)**
Unclassified	**14 (4.7%)**	**10 (0.4%)**

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Marie: Causes of staff distress

- Sheer impact of the behaviour
- Not understanding the causes of the behaviour
- Magical beliefs in the power of psychotropic medication, and consequent helplessness
- ‘Duty of care’ to meet her demands
- Anger at her ‘selfishness’
- Night staff beliefs about the necessity to change her, and about getting into trouble with day staff

What happens in residential care?

STAFF → **PATIENTS**

Staff care for people with dementia

What really happens

Staff

Feelings

Behaviour

Attitudes

Knowledge

Skills

Level of support

Person with dementia

Feelings

Behaviour

Past experience

Impairment level

Medical/physical state

Characteristics of staff (e.g. behaviour, feelings, attitudes) and characteristics of residents are in a dynamic symbiotic relationship. Staff welfare and resident welfare are inextricably mixed.

Development of Strains in Dementia Care Scale

- Original ‘Strains’ scale developed in Sweden in 1996. Translated 2002 for Australian use.
- New scale items developed from focus groups of dementia care staff in Australia, Sweden, UK. Yields 64 items
- Given to 1000+ residential and community care staff in Sweden and Australia
- Data analysed using factor analysis to reduce number of items to a more sensible number

“We had this man, he never said anything, he was quiet and introvert and he tried to open all the doors everyday, trying to go home. And then one day, he waved at me and said, - Do you know Johannesson, and I said - No. He said - He was my neighbour, and I said - No, I don’t think I know him. He said, - Well do you think you could call him? I said, - Yes, was it anything special? And he answered - Well you know, he has a dammed good gun, could you phone him and ask if he could come over and shoot me? There was, sort of, nothing more to add. It happened about ten years ago, maybe more, but I still remember…”

“I think it is very stressful when one is going to help someone that just holds on, you are trying to take the trousers down at the same time as she is holding on to her trousers… you explain and explain but they just get more and more frightened… and maybe it’s because of pain… one never knows”

” ... your job is so much more than that [the nursing care of patients with dementia], you are dealing with your colleagues, all the external factors, the families, money frustrations, equipment not working, problems at home which you bring into work. The clients, it’s quite a wide aspect of your day, a big one, but not the only thing that that makes life difficult ...”

” I think it’s about being able to provide what these people should be entitled to, and we can’t provide it because of the system and if it was an ideal world we could have all the resources… and we’re never going to change the world and have all the resources… but I find it very frustrating that these people lived their lives, experience all these feelings and come to the stage where the illness... and I don’t think they get what they are entitled to and yet all the nurses do the best of their abilities but there is still a big missing chunk of things that these people should be provided with”

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Demographics

	Sweden	Australian Facilities
No. of Participants	629	223
Age	43.89	42.48
Gender	F=89.00% M=6.50%	F=94.3% M=5.67%
Years of experience	11.94	7.89

Most Stressful Aspects of the Work for Australian Staff

- I cannot do as much as I want to for residents because there isn't enough time
- The families of residents/clients do not seem to understand how difficult it is to care for their relative
- I see that a resident/client is suffering
- I do not have enough time or resources to meet the emotional needs of the family and residents
- I see other staff behaving towards a resident in a way that shows they do not understand the affects of dementia.

Results of Factor Analysis

Factors

- Empathy and Protection
  - Items 42, 55, 56, 57, 58, 61, 62, 63, 64
  - (e.g. I see that a resident/client is suffering)
- Difficulty Understanding
  - Items 7, 15, 16, 17, 18, 20, 22
  - (e.g. I find it difficult to understand what residents are experiencing or feeling)

Factors (cont.)

- **Tough Love**
  - Items 23, 25, 26, 27, 32
  - (e.g. I have to do things against the will of a resident; Have to balance the needs of a resident against the needs or demands of other residents)
- **Systemic Problems**
  - Items 5, 8, 9, 11, 14, 52
  - (e.g. I feel that I do not receive enough support)
- **Emotional Involvement**
  - Items 19, 34, 38
  - (e.g. When a resident/client dies or has to move I feel as though I have lost a close relative or friend)

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Summary to date

1. **Based on relatively recent research focus on the relationship between staff distress and behaviour, and resident distress and behaviour in aged care.**

2. **Resident behaviour is only one of several variables which cause stress. Staff and organizational variables are as important, including the level of skill and attitude of hands-on carers, and the amount of support given them.**

3. **There is good research showing that many of these variables are remediable, in particular by education and emotional and practical support of staff.**

Hallberg and colleagues: Clinical support and supervision study

Preliminary work shows:

- Excellent physical care
- Very poor social interactions (task oriented)

BUT

- Staff show evidence of care and empathy.

The problem is perceived helplessness to relieve residents' psychological distress.

Hallberg and colleagues: Clinical support and supervision study

Intervention aimed at:

- Increasing understanding of each residents' individual physical and emotional needs
- Care plans based on residents needs rather than the management problems they present
- ENs assume much greater responsibility for developing and implementing care plans, and for resident advocacy

Hallberg and colleagues: Clinical support and supervision study

Outcomes

- Improvements in:

Staff morale, job satisfaction, job creativity, quality of care interactions, quality of nursing care, and resident mood.

- Decreases in:

Staff stress, task-oriented nursing, and difficult resident behaviour

Replication of the ‘Lund’ model: Adaptation to Australian conditions of a clinical supervision and individually planned dementia care approach

Michael Bird, Annaliese Blair, Tanya Caldwell, Gaynor McNess, & Chris Burt

NSW Southern Area Health Service
and
Australian National University

Original Study: A Rolls Royce Model

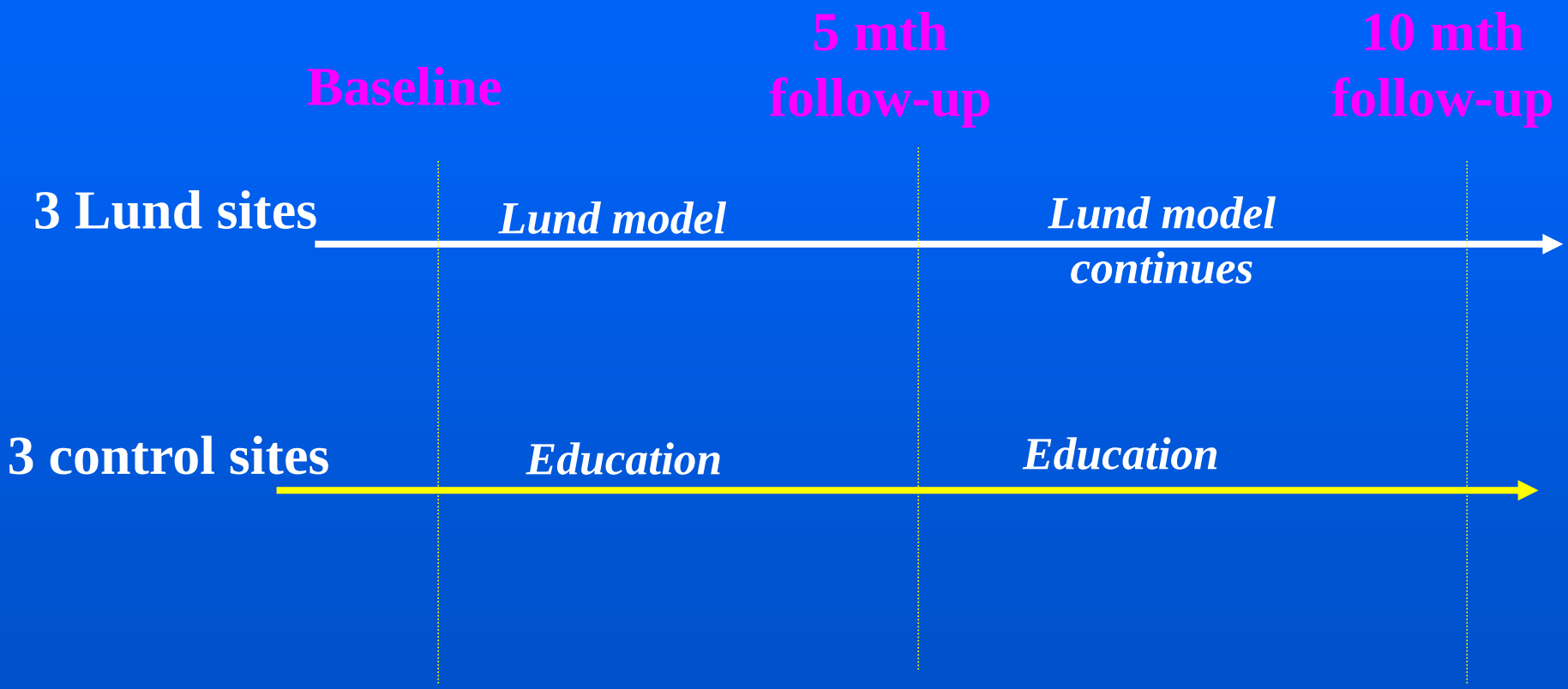
- **An 11 bed ward only**
- **All staff on duty released for two hour supervision sessions once a fortnight. Positions back-filled**
- **Two BPSD-literate RNs spend two hours a week on the ward working with a key staff member to devise care plan tailored to residents needs**
- **Staff are ENs with two year's training, and staff ratios much better than current-day Australia**

Australian version

Delivered by Pat Murdoch of Hammond Care at afternoon handover once a fortnight.

- **Sessions starting from 'who is this person', and the view-point that the disturbed resident discussed is probably suffering**
- **Staff encouraged to share their fears/concerns/distress**
- **Identifying the nature and physical-medical and/or psychosocial causes of the resident's suffering, and brain-storming to devise a feasible care plan which addresses it**
- **Encouraging more autonomy in ENs and AINs in responsibility for developing and implementing the care plans**
- **Pat spends about 2 - 3 hours in the unit a fortnight helping staff devise care plans.**

Planned Design



Measures

- **Staff burnout, stress, and attitude**
  - **Maslach Burnout Inventory**
  - **Behaviour Stress Scale**
  - **Strains in Nursing Care Scale**
- **Care Practices**
  - **The Nursing Unit Rating Scale (tolerance, continuity, flexibility)**
  - **Restraint use**
  - **Nature of staff response to reportable incidents**
- **Resident behaviour - The NeuroPsychiatric Inventory (NPI)**
- **Medical practitioner visits, frequency of changes to psychotropic medication**

Main results: T1-T3

'Pure' sample: 1 Lund & 2 control sites over full study period

- **No change in behaviour (but close)**
- **Reduction medico visits and med changes**
- **Reduction in use of physical restraint remains (Lund superior but due to different samples)**
- **Reduction hostile factor on attitude scale**

No difference any other measure.
No significant group effects

Focus Groups

Held with staff who took in both conditions 9 – 12 months after the programme

Clear difference in qualitative comments

- **'Lund' group still remember many aspects of Lund sessions,**
- **Some 'education alone' staff cannot distinguish the sessions from other workshops they've been to**

What Control sites said: Focus groups

- Education needed for new staff not us
- Learned some strategies
- Good to hear it all again but partly waste of time
- Good to meet people from elsewhere and share problems
- We need case discussions and sharing information about residents
- We get no emotional support and little practical support
- Not specific to their residents and hard to apply principles if no support to do so

Education alone

Like more knowledge is very very helpful for the residents…plus us as carers because it makes our job easier because we're doing it right…

I guess it reinforces what I knew. I knew how that should be done. It just reinforces that we're on the right track

Really good…I still use what I learned today… When they're upset I use the five principles. I still do that now with my residents and I didn't realise until I did the training

…that initial training before they come on the floor – it's not there at the moment

Control group

- ***Our unit meetings have got to be restructured. Instead of talking along those sort of lines, we're talking about the bloody laundry and all the things that don't really matter at the end of the day. […] We don't talk about the "serious stuff" […] like the care plans, the care issues, the consistency and umm interacting with one another, what works and what doesn't work.***

What Lund sites said: Focus groups

Case histories and group discussions lead to :

- **More strategies**
- **Better understanding of residents (social history crucial)**
- **Emotional support and feeling valued/sharing distress and admitting to feeling inadequate or frightened**
- **More cohesive teams**
- **Improved relationships with families**

Lund groups

People who had been there for a long time were able to see that the person was frightened and I think it became more of a team effort to actually look after each person then. You felt very comfortable expressing how you felt in those groups. I think it built a stronger team, sure.

Lund

- **Staff 1.** ***Sharing...that we weren't the only ones that felt frustrated or sad or whatever.***
- **Staff 2.** ***That's exactly what I was going to say…***
- **Staff 1.** ***Just that…***
- **Staff 2.** ***We realized that we were all in this together.***
- **Staff 1.** ***And that it's OK to have…***
- **Staff 2.** ***Good days and bad days***

Lund groups

Knowing her past history though, and where she'd been, it's almost like she'd been to hell and didn't come back from there. […] it gave me a better understanding of where she was and her mind and what she had to go through during the war and…yeah it gave me the strength to keep going and to try each day with her […] just to be tolerant and take her into your heart […] Because in the beginning I was nearly ready to give up [laughter]…thinking, 'Oh! I dunno if I can do this'.

Lund

Before Pat started sessions I felt very useless and unappreciated in my work place. I think that over the months she came she was able to make the RNs I work with realise the value of my work and the difference that it makes

I always felt good about myself after attending Pat's sessions. Pat made us all feel worthwhile and important

Made our feelings and self-worth increase, talking about our worries for a session was good. She made us think of our clients as people

Take-home message

- Residential care staff need to be looked after: They deserve it both for themselves, and for the sake of the people we entrust to their care.
- We think we know a systematic way to help them, based on the Lund study and similar projects

BUT

In Australia at least, it's increasingly difficult to undertake systematic interventions to help them