How you want to be treated.

Conflicting needs in the LTC environment: Effects of mixing people with diverse forms of dementia

Sharon Koehn, Ph.D.
Jean-Francois Kozak, Ph.D.
Elisabeth Drance, MD, FRCPC

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Learning Objectives

The participant will be able to:

- Identify elements of each of the physical, psychosocial and organizational environments in long-term care that exacerbate dementia-compromised need-driven behaviors and how these differ for people with Fronto-Temporal Dementia (FTD) and Alzheimers' Disease and Related Dementias (ADRD)

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Learning Objectives

The participant will *also* be able to:

- Describe the myth of homogeneous “homey-ness”, i.e. describe the resident needs that can become perceived barriers to achieving “homey-ness” in special care units
- Debate the appropriateness of mixing people with different dementia aetiologies in SCUs vs. the segregation of people into more homogeneous populations based on behavioural needs or diagnoses.

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Challenging Behaviours or Unmet Needs?

- 90% of patients affected by dementia will experience behaviours and symptoms severe enough to be labeled as a problem during the course of their illness. These include:
  - Uncooperative Behaviour
    - Suspiciousness/Paranoia
    - Stereotyped Vocalizations or Screaming
    - Wandering
    - Agitation
    - Aggression
    - Hallucinations
    - Sleep Disorders

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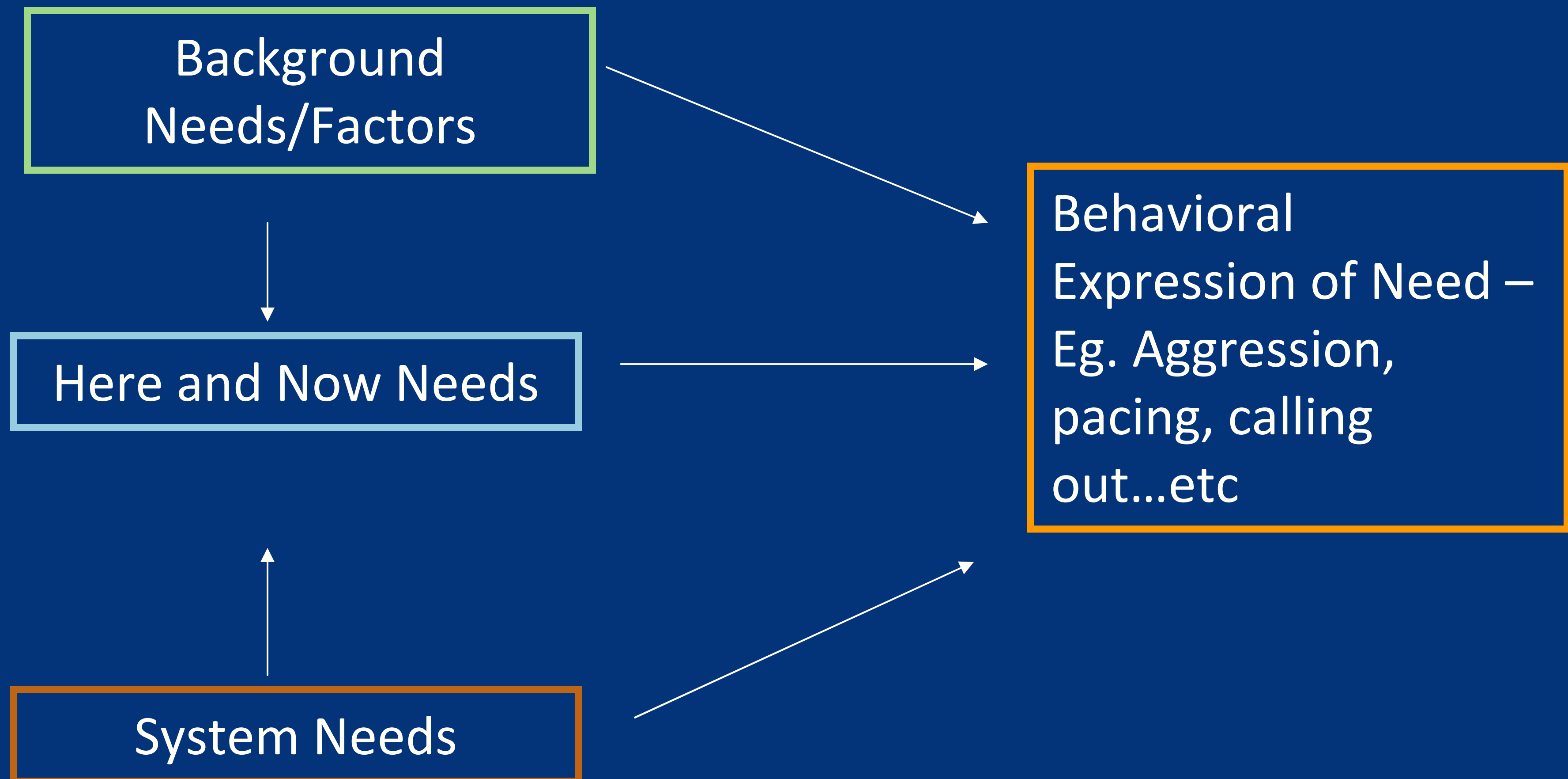
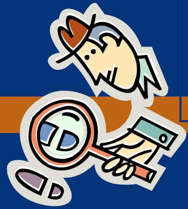
The Need Driven Dementia-Compromised (NDDC) Behavior Model





NDDC Behavior Model

Background Needs

Cognitive Strengths & Challenges

Psychiatric Needs

Medical Needs

Medication Needs

Psychosocial Needs

Personality Needs

Spiritual/Cultural Needs

Here and Now Needs/Triggers

Emotional Needs

Physiological Needs

Psychiatric Needs

Physical Environment

Social Environment

System Needs

Focus on Task

"Doing to" rather than "helping with"

We are the experts

For residential Care -poor match between staffing levels/service hrs/ training & complexity

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Study: Modifying a Special Care Unit for Dementia

- Decreased institutional appearance
- Improved bathing experiences for elders and those who assist them
- Improved dining experience
- Improved social environment
- Improved access to outdoor patio space and functional garden beds

Effects?

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Project methodology

Mixed methods approach:

- Quantitative data from environmental inventory and patient records
- Qualitative data from ethnographic approach: participant observation, personal interviews and focus groups

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Qualitative component

- 77 hours of participant observation
- Two sets of focus groups with (a) nursing staff and (b) family members
- Five personal interviews with other staff / paid companions
- Series of short interviews with 3 residents over duration of research

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"The Problem with Leonard'

- A case study of a resident with behavioural variant frontotemporal dementia: How he affects and is affected by the environment of the SCU

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Behavioural Variant Fronto-temporal Dementia (bvFTD)

- Onset typically in the 50's
- Characterized by early & progressive:
  - Changes in personality
  - Difficulty in modulating behaviour to match social context
  - Emotional blunting +/or loss of empathy
  - Word-finding language difficulties may be present
- Memory impairment is far less prominent than in Alzheimer Disease

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Behavioural Symptoms of bvFTD

- Hyperoral behaviour
- Stereotyped and/or repetitive behaviours
- Personal hygiene decline
- Pacing & Wandering
- Outbursts of frustration +/- aggression
- Hypersexual behaviour
- Impulsive acts – shoplifting, impulsive buying, grabbing off others' plates.

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Emotional Symptoms of bvFTD

- Apathy
- Lack of insight
- Emotional blunting
- Indifference to others, including loved ones
- Abrupt/frequent mood changes

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Leonard as “the problem”

- In each of the interviews that we conducted with staff and family members, Leonard’s NDDC behaviours arose as a dominant theme, particularly
  - Compulsive food seeking and excessive eating (particularly for sweet foods);
  - Impulsivity and hoarding;
  - Selfishness or the loss of the ability to empathize with others

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Compulsive eating and the threat to homey-ness - STAFF

Vera: Actually, one thing I don't like is the lock on the fridge - that's my pet peeve! [laughs]. I cannot stand it, because at home we don't have a lock on the fridge...

Estelle: I agree with what you're saying, but the biggest picture of it, everybody deserves to have some kind of refreshment.

Vera: So that's why we need two kitchens: one here and one somewhere else

(Staff focus group, 26 October 2007).

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Compulsive eating and the threat to homey-ness - FAMILY

Lisa: They had to lock [the fridge] up because [Leonard] will drink all the milk and all the orange juice and then go in the freezer.

Amy: Yeah I think they just locked it.

Lisa: Well they do but they don't always lock it. And it's unfortunate.

(Family focus group, 3 December 2007).

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Compulsive eating and the threat to homey-ness - FAMILY

Karen: He takes my Mom's candy, and chips and cookies. Like if I take her in extra food because I always worry about her eating, he just comes into her room and takes it.

Mandy: Or I left my lunch there one day and came downstairs for awhile and it was gone.

Karen: Oh yeah, everything's always gone

(Family focus group, 3 December 2007).

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Impulsivity and hoarding - FAMILY & STAFF

"We bring him down for the games like for the shuffleboard or for entertainment and all that and I'll, … say I'm going up to [the neighbourhood] so I'll take Leonard back . . . [and] on the way, he will take everything off the wall. He'll take flowers, or anything, he's taking it, he will not listen to me; . . . when I tell him to put things back he'll put it back but he's already got another one! And it just keeps going, you know" (Lisa, Family focus group, 11 June 2008).

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Framing Leonard as devious - STAFF

"[Another resident with AD] took also sometimes he went to people's apartment and rooms and took things out … but he did it … because his brain was not there clearly he didn't know exactly what he was 100% doing as I think some people know more what they are doing … who have a certain control over something and they do still the same thing, it's different"

(Personal i/vw – non-LPN staff, 28th August, 2008)

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Framing Leonard as devious - FAMILY

- Leonard "puts a damper on a lot of things on that floor, you know, he's almost too aware"

  (Family focus group, 3rd Dec 2007).
- Re: inappropriate sexual behaviour: "One of the nurses said to me, 'Don't overlook the fact that he might be doing that just to get off this floor'"
- "He is extremely clever … He's on the ball."

  (Family focus group, 11th June, 2008)

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Muted empathy and optimal stimulation

Sophie: Last week, [an]other resident was yelling like 'Where's the volume, I can't hear it? Where's the volume?' so she went and, and started pressing the wrong button and the volume was … all the way high!

Bill: And if you put it on a program or we've set it to a movie it would be changed to the programming that is to the liking of [Leonard]. … So if it was, say, on any type of show that somebody is there before, he'll come after, and change it…. And everyone just sort of sits and goes along with it. …I don't know if they know what to do.

(LPN focus group, 22 January 2008)

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The *real* “problem with Leonard”

- Leonard’s ‘reality’ is co-created by everyone who spends time on the neighbourhood, including the families of other residents, hired companions, and nursing staff.
- ‘Power’ is distributed hierarchically among them with Leonard’s voice silenced by healthy others.
- Contributing factors include:
  - A lack of understanding of FTD
  - Organizational dynamics, incl. biomedical vs. person-centred orientation, staff ratios, qualifications and training

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Implications

- A NDDC model provides a framework for understanding behaviours
- Appropriate physical environments are necessary but not sufficient to create homey-ness
- Power dynamics influence social relationships & dementia-related behaviours
- One size does not fit all – environments must be flexible so as to accommodate the changing needs of diverse populations of people with dementia

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Implications for Participant Discussion

Debate the statement:

It is wiser to group elders with frontotemporal dementia together in living environments than to disperse them in small numbers throughout standard special care units.

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Forthcoming article

- Koehn, S., Kozak, J.-F., & Drance, E. (in press). The problem with Leonard': A critical constructionist view of need-driven dementia-compromised behaviours. *Dementia: The International Journal of Social Research and Practice.*
- Sharon Koehn: skoehn@providencehealth.bc.ca
- Slides available at: http://centreforhealthyaging.ca/

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