

Relational Understandings of Personal Expressions

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- Persons with dementia

Objectives

1. to examine the understandings of and language used to describe the actions of persons with dementia
2. to explore where this language and dominant understandings are rooted
3. to identify some of the consequences of the dominant discourse/understandings for persons living with dementia
4. to consider what an alternative discourse and relational approach might look like and mean for persons living with dementia and care partners



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Dementia troublemakers problem in retirement homes



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A growing proportion of retirees with dementia are turning out to be a menace to themselves and other retirement home inmates.

by Christopher Jay

The federal Department of Social Services and retirement home proprietors are bracing themselves for one corollary of the inexorable progression of elderly baby boomers into the advanced age groups of the over 70s and over 80s – a surge of feral geriatrics with severe and often violent behaviour problems stemming from dementia.

Elderly people with various forms of dementia are more typically seen as being vaguely harmless people with fading memories, hardly a threat to anyone. But as the tidal wave of people moving into retirement homes expands, a proportion are turning out to be a menace to themselves and other retirement home inmates – mad, bad and dangerous to know.

Reflective Exercise #1

- On your own or with the person sitting next to you, take one minute to list all of the words you know of associated with “behaviours” in the dementia context.
- Consider the following question:
 - What language have you used or know others have used to talk about and describe the actions of persons living with dementia?

Confabulation

DANGEROUS

MAD

disruptive

AGITATED

wanderer

menace

demented

Troublemaker

TOTALLY DEPENDENT

Violent

challenging

repetitive

Hoarder

Ticking time bomb

Non-compliant

unresponsive

lethargic

A Baby

AGGRESSIVE

DISTURBING

screamer

Pathologisation of Actions

“What really had an impact on me was really understanding the physiological aspects of dementia and the different types of dementia and how each one affects different areas ... I’m able to say OK this person’s going to have these types of problems or challenges. I found that very helpful for me because it grounds me in my knowledge and I’m able to get ... past the person, you know, it’s a disease process.”

Pathologisation of Actions cont'd

“I think she’s going through the third stage of Alzheimer’s right so it’s just a matter of time that she would just stop doing that, but I guess it’s just a stage that they have to go through ... It’s like trying to figure out what’s wrong with a crying baby...They can’t tell you what’s wrong. They’ve been fed, watered and changed and they’re still crying.”

Pathologisation of Actions cont'd

“I really believe that the residents aren't aware of their behaviors. I really feel that their behaviors aren't an issue for themselves. The behaviors of the residents are as a result of either physical deterioration or... being agitated because of a reason and I don't think residents are very aware of their behaviors. I could be way off but I don't think they are aware or frustrated by it.”

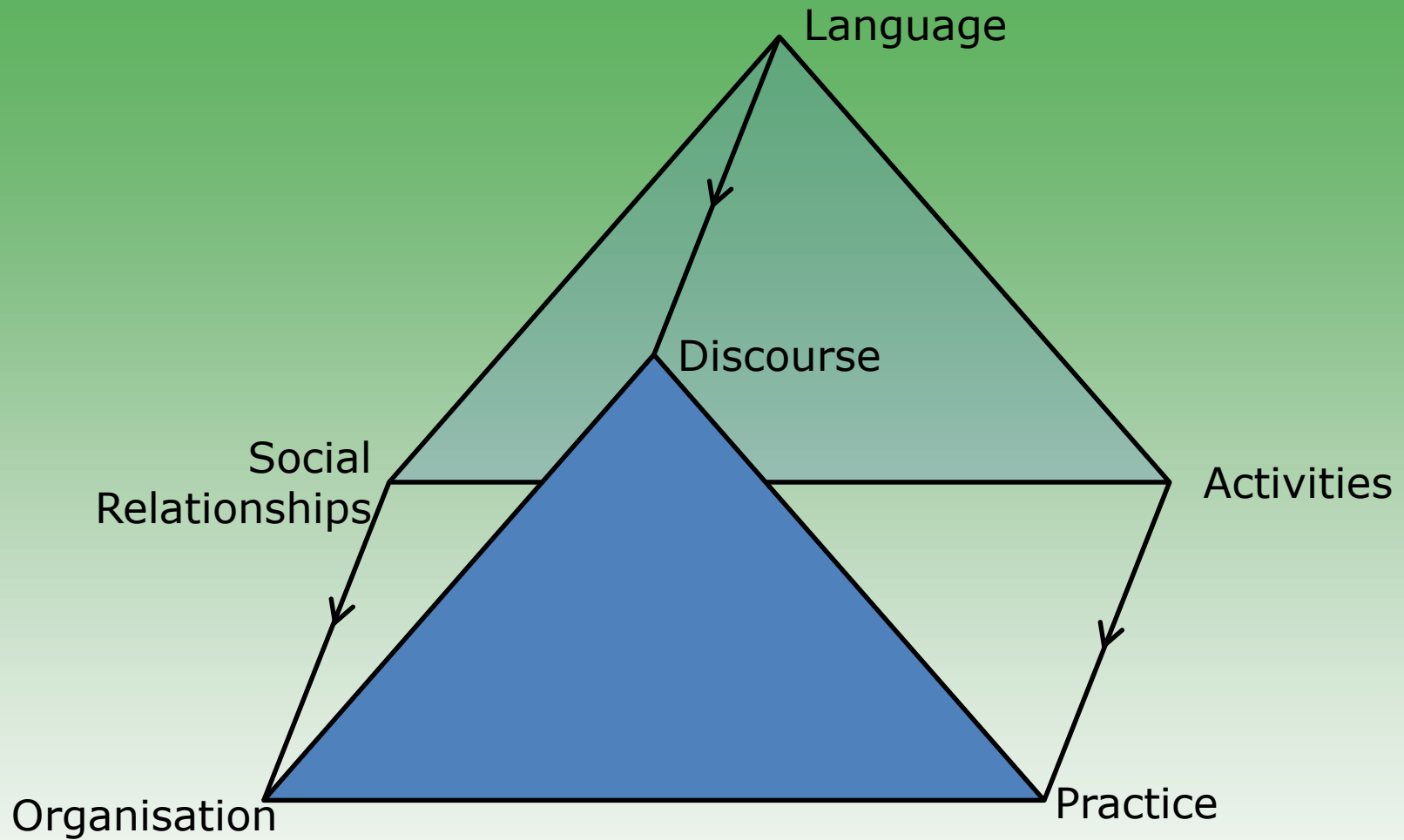


Figure 1: Interdependencies Between Words, Activities and Relationships (Kemmis & McTaggart, 1988)

Consequences of the Dominant Discourse

- Influences how persons with dementia view themselves and their lives
- Shapes how persons with dementia and their actions are perceived and judged by others
- Impacts/changes how the person is treated
- Limits the choices and opportunities available

Consequences of the Tragedy Discourse

- Persons are dismissed and ignored
- Persons are silenced – attempts to communicate with the person stop
- Remaining abilities are not seen/overlooked
- Persons are treated like children/overprotected
- All actions are viewed as symptoms of the disease
- Persons and their actions are labeled, categorised and judged

Public Use of Whiteboards

Rectangular Sign

RESIDENT	BEHAVIOUR(S)	TRIGGERS	IMPLEMENTATION(S)	CURRENT SHIFT STATUS	MEDICAL	RISK
H.P 1078 Dr. Bera	→ UNWANNING → COLLECTING ITEMS/PAPERS → ...	→ ... → ...	• SET UP PC CHAIRS • ... • ...			
J.A RM 0105 DR. MINOR	→ Sexually inappropriate behaviours of staff & residents → suspicious of others and transparent	Recent issues Δ in environment LOSS of independence	See DAY in the life Say hello when walking by Do a few more tasks to help Do a few checks Promote homes act & engage in stimulation			

RESIDENT REMINDERS

M.M

ENSURE SHE IS SET UP WITH AN ACTIVITY TO STIMULATION (WELL COMPLETE PEOPLE'S INDEPENDENTLY ONCE SET UP FOR STIMULATION/REMINDERS)

M.B

SET UP 2 AN ACTIVITY BEFORE SNACK TIME (GAINING OUT NOTE TO ESTABLISH AN ACTIVITY FROM AVAILABLE)

RED NOTE IS NEEDED IF CHANGING ABITATION/RESPONSE BEHAVIOURS PLEASE PROVIDE DETAILS ON INTERVENTIONS THAT WERE IMPLEMENTED TO REDIRECT

↳ IS EFFECTIVE OR NON-EFFECTIVE ACTIONS THAT WERE TAKEN

EJ & HJ

→ ...

→ ...

→ ...

WORDS OF THE WEEK

BEHAVIOURAL INTERVENTIONS

- ↳ Offer attention
- ↳ Your Response
- ↳ Increased Control

↳ ...

↳ ...

↳ ...

Consequences of the Tragedy Discourse

- Force used to control “undesirable behaviours”
- Clinical interventions and treatments the focus
- Life long and valued activities become therapy
- Persons are treated as objects
- Person’s choices not respected

When you change the way
you look at things the things
you look at change.



As words change,
so do perceptions,
and as perceptions change
so do ***actions***

(Fazio et al., 1999, p. 5)

Reframing “Actions” in the Dementia Context

Problem-Based Discourse	→	Possibilities Discourse
Anxiety	→	<i>Eagerness</i>
Agitation	→	<i>Energy</i>
Wandering	→	<i>Exploring</i>
Garbled, repetition	→	<i>Poetry</i>
Disruptive/Challenging	→	<i>Communicating</i>
Hoarding	→	<i>Collecting</i>
Aggressive	→	<i>Protecting self</i>

(Adapted from Fazio et al., 1999)

Personal Expressions of Self and Experiences

1. All personal expressions (words, gestures, actions) have meaning.
2. Personal expressions are an important means of communicating meanings, concerns, lived experiences, memories, and valued aspects of the self – an embodied selfhood.
3. Personal expressions are embedded in, influenced by, and reflect relationality – our multiple relationships.
4. A multidimensional, layered, contextual lens is needed in order to understand and appreciate what is being experienced and expressions of experiences.

Relational Context

Space/Physical Environment

Our Bodies

Objects

**Ideas/
Values**

**Higher
Being(s)**

**Experiences
IN
Relationship**

People

Time

Animals/Other Living Beings

What are the implications of a relational approach?

How might understanding the personal expressions of persons living with dementia through a relational lens change how we respond?

Relational Caring

Caring through Voice and Spoken Language

- providing persons with information, explaining what we are doing and why
- simplifying language and tasks
- reducing amount of information given
- being gentle/using a calm voice and manner
- using empathetic listening and repeating words or phrases the person has used
- being attuned to the language we use and the implications of that language

Relational Caring

Caring through Body Language

- approaching person from the front
- getting down to person's eye level
- using physical affection and calming touch
- modelling what we want them to do
- being attuned to what our bodies/body language might be communicating to the person
- recognizing how important aspects of the self and experiences are expressed in and through the body by persons with dementia

Relational Caring

Caring through Nurturing Reciprocal Relationships

- being open to mutual influence
- nurturing relationships built on trust, patience, compassion, respect, reciprocity
- being authentic in relationships
- being responsive
- working to empower others
- showing interest in the person and his/her life
- providing meaningful experiences/interactions so the person can continue to feel useful and valued
- asking for help and support
- using collaborative decision-making and problem-solving
- being aware of own needs as well as the needs of others

Relational Caring

Caring through Being Relationally Present

- believing that the person is “still there” and in their continued abilities
- respecting and being able to move in person’s realities
- moving with the person’s rhythms, slowing down
- being flexible in routines and ways of living
- knowing and respecting individual preferences, biographies and histories
- being emotionally present
- building anticipatory empathy
- being attuned to contextual factors

Ethical Considerations

- Will the decision/response harm, in any way, the person's sense of self? If so, how? If not, how do you know?
- Will the decision/response harm, in any way, the person's relationships with others? If so, how? If not, how do you know?

How might a relational understanding of personal expressions change how you respond?



Thank You!



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Sources

- Dupuis, S.L., Wiersma, E., & Loiselle, L. (2012). Pathologizing behaviour: Meanings of behaviours in dementia care. *Journal of Aging Studies*, 26(2), 162-173.
- Dupuis, S.L. (2015, May). *Relational understandings of personal expressions in the dementia context*. Invited workshop for the Dotsa Bitove Wellness Academy, sponsored by The York-UHN Academy and the Lorraine Johnston Fund. Toronto, ON.
- Fazio, S., Seman, D., & Stansell, J. (1999). *Rethinking Alzheimer's care*. Baltimore, MD: Health Professions Press.
- Jordan, J., Walker, M., & Hartling, L. (2004). *The complexity of connection: Writings from the Stone Center's Jean Baker Miller Training Institute*. New York, NY: The Guilford Press.
- Kemmis, S., & McTaggart, R. (1988). *The action research planner* (3rd ed.). Geelong: Deakin University.
- Kontos, P. (2006) Embodied selfhood: An ethnographic exploration of Alzheimer's disease., In L. Cohen and A. Leibling (eds.) *Thinking about dementia: Culture, loss, and the anthropology of senility*. New Brunswick, N.J: Rutgers University.
- Kontos, P. (2005) Embodied selfhood in Alzheimer's disease: Rethinking person-centred care. *Dementia: The International Journal of Social Research and Practice*, 4(4), 553-70.
- Mitchell, G., Dupuis, S.L., & Kontos, P. (2013). Dementia discourse: From imposed suffering to knowing other-wise. *Journal of Applied Hermeneutics*. Accepted in January 2013.
- Wells, K. (Sunday, November 18, 2012). Dementia Care in Denmark. CBC Radio. <http://www.cbc.ca/player/Radio/The+Sunday+Edition/ID/2304600853/>.