

Quality of life for the person with severe dementia: A collective case study approach.

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Outline of the study



- FAST stage 7a–7f, defined as the stage when "*the cognitive deficits are of sufficient magnitude as to compromise an otherwise healthy person's capacity to independently perform basic activities of daily life. Such as dressing, bathing and toileting*" (Reisberg et al., 2006; 83)

What is known about quality of life in severe dementia?

It is underrepresented in research, education and policy.

The main focus is on normative rating scales and tools to measure objective outcomes.

Most qualitative studies do not address this period.

There are no studies of quality of life exclusively about the person with severe dementia.



Research question

What can be learned about quality of life for people with severe dementia living in a care home, using a case study approach?

Design and methods

- Qualitative, collective case study design (Stake 2010)
- Multiple methods included:

Interviews

Observations

Routinely gathered data

Rating scales

Field notes

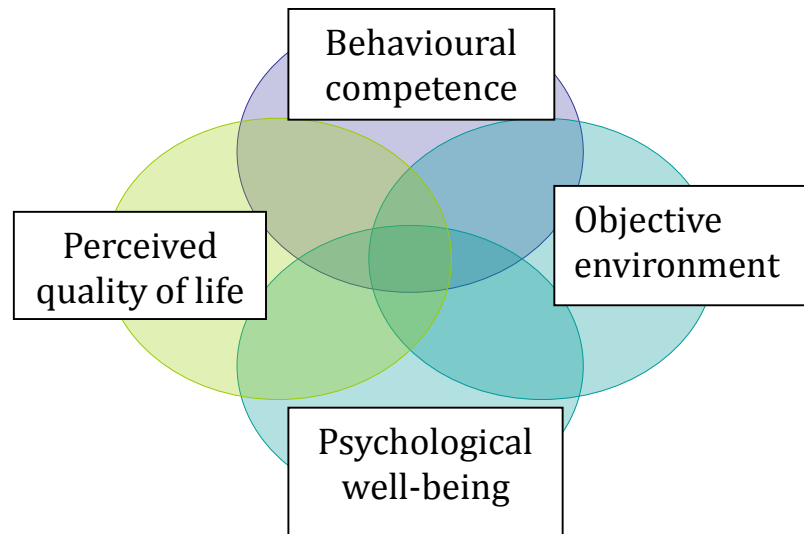
Stake, R.E. (2010) Qualitative Research: Studying how things work. New York: The Guilford Press.

Data management



Data Analysis

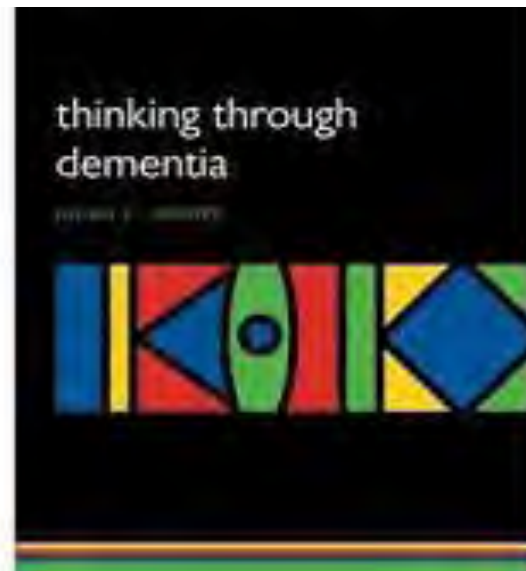
- Dimensions of quality of life (Lawton, 1994)



Data Analysis

The Situated Embodied Agent

The SEAVIEW of the person with dementia.



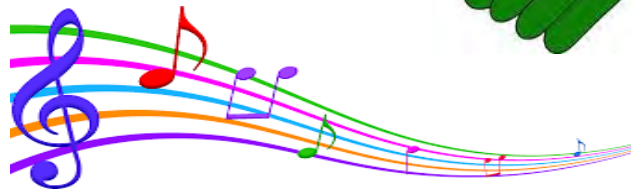
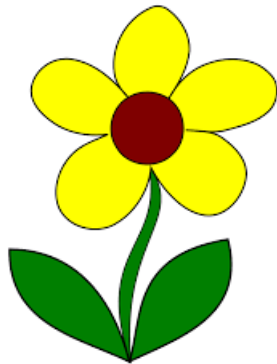
Data analysis

- First level analysis: coding using Lawton's theory (1997)
- Second level analysis: elaborative coding using the lens of the situated embodied agent (Hughes, 2011)

Hughes, J.C. (2011) Thinking through dementia. Oxford: Oxford University Press

Lawton, M.P. (1994) Quality of Life in Alzheimer Disease. Alzheimer Disease and Associated Disorders. Vol. 8(3), pp. 138-150.

Case Study Reports



Cross Case Analysis : Findings and Themes

Cross case themes	Mrs Flower Findings	Mrs Gardener Findings	Mr Artist Findings	Mrs Walker Findings	Mrs Musician Findings	Mrs Cook Findings
1. Expressing and discerning needs	"You have to think she is ok": understanding needs	"Trying to tell you": recognising need		"Down and up": changing needs	Responding to the senses: changing needs	Well here I am: recognising needs
2. Complex care needs in severe dementia		Do not disturb: experiencing unwelcome care	"Holding on like grim death": the experience of unwelcome care	"Take the pain out": complex care needs.	Clouded by illness: responding to complex needs	
3. A sense of connection and engagement	"I'm still here you know": making connections	"On standby": connections are made	He has his moments: connecting with his world	A different bond: Feeling connected	The best we can do: keeping connected	My own wee world: need and connection
4. Interpersonal relations in the life of the person with severe dementia	The same as before: knowing the person	"Echoes of the past": seeing the person	"He can still do things": maintaining the person	What do you expect?: recognising the person	Living from moment to moment: the changing person	"Oh she is singing": keeping the person.
5. Illusions of home in severe dementia.			"A familiar surround": a kind of contentment			Going to mum's house: A sense of home

Assertions in case study research.

Assertions are statements arising from the analysis, not only rooted in the data but also integrated with existing knowledge and understanding to move the topic forward and generate directions for further research.

Assertions

Assertion 1 : The body, the senses and the narrative matter.

Assertion 2: Note and share the small things.

Assertion 3 : Manage and maintain the fragile balance.

Assertion 4 : Seek a new perspective to deepen understanding.

Assertion 1.

Observable dimensions of quality of life can be discerned using sensory and embodied experiences, grounded in past and present knowledge of the person with severe dementia.

Assertion 2.

Family and care staff can influence quality of life when there is a shared and nuanced understanding of the small things that make a difference in the moment of care.

Assertion 3.

Shaping quality of life for the person with severe dementia involves recognition that the fragile balance of influencing factors must be continuously monitored and refined.

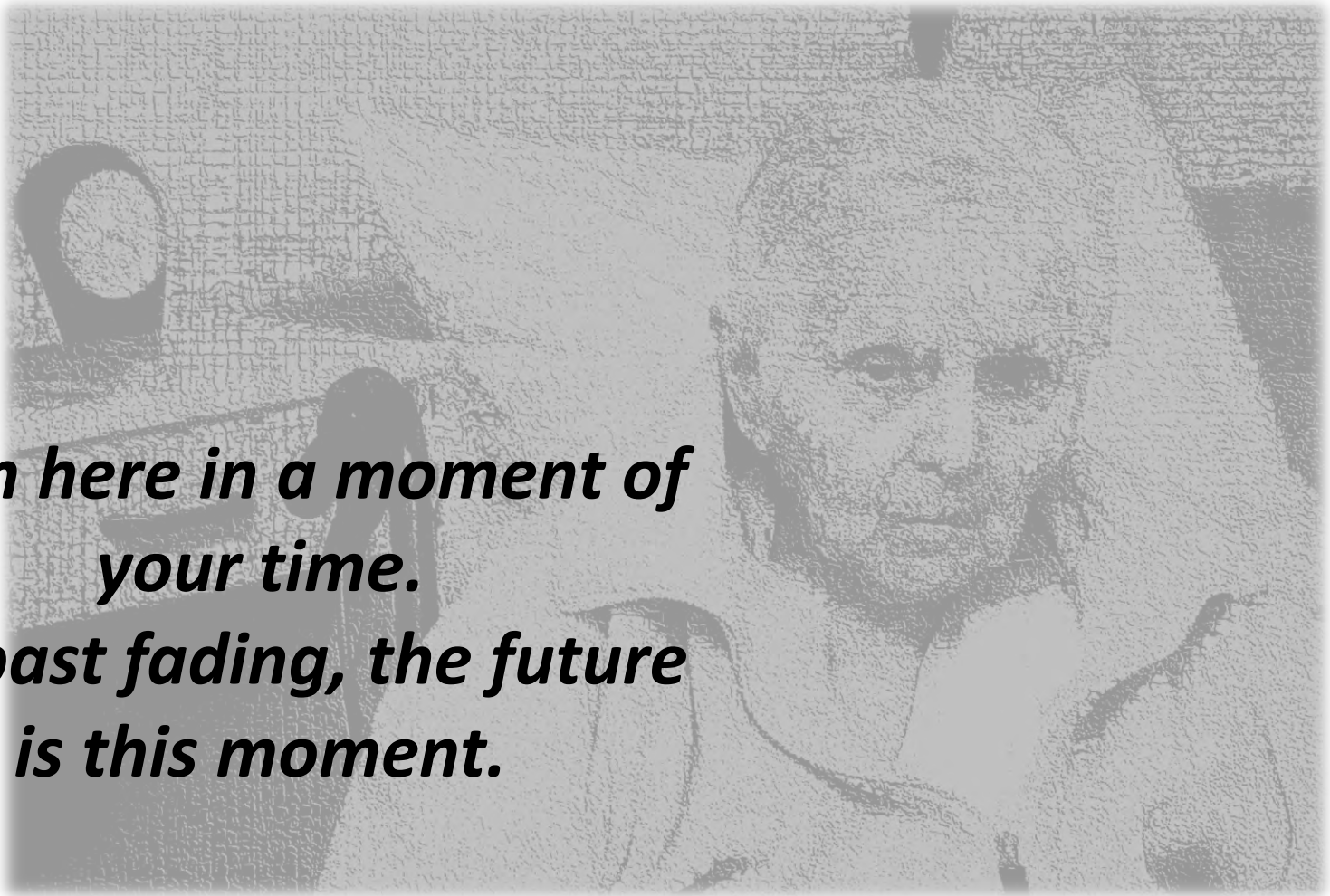
Assertion 4

Quality of life for the person with severe dementia is complex and multidimensional and at this stage of the condition in particular there is a need to refocus through a new perspective to deepen understanding of the experience.

Reflections

***" I am here in a moment of
your time.***

***The past fading, the future
is this moment.***



So what?

Welcome Care is in the NOW!

- Fundamental aspects of care are the opportunities to improve the experience...
- Sensory, embodied care can optimise impact.
- Note, Share, Communicate, Understand.

What next?

Focus on 'what makes care welcome?'

Determine sensory, embodied assets, 'note and share'.

Explore means to make emotional connections among family staff and the person with severe dementia.

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