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Mikelyte, Rasa (2018) Corporeality, Embodiment and Mealtimes in NHS Continuing Care for People with Dementia. In: British Sociological Association Invisible Bodies One Day Conference, 7 September 2018, Canterbury, UK. (Unpublished)

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CORPOREALITY, EMBODIMENT & MEALTIMES

in NHS Continuing Care Wards for People with Dementia







RESEARCH SUMMARY

The research project aimed to collaboratively develop small-scale interventions that will improve meals and mealtime experiences for people with dementia, their relatives, and ward staff in two NHS Continuing Care facilities.

- **Example** interventions involved:
 - Changes to when and what type of food is available
 - ❖Mealtime environment (e.g. table layout)
 - Opportunities to share and interact during mealtimes

All changes decided by the stakeholders

CONCEPTUALISING MEALTIMES

Nutrition & Hydration;

Eating Ability & Assistance

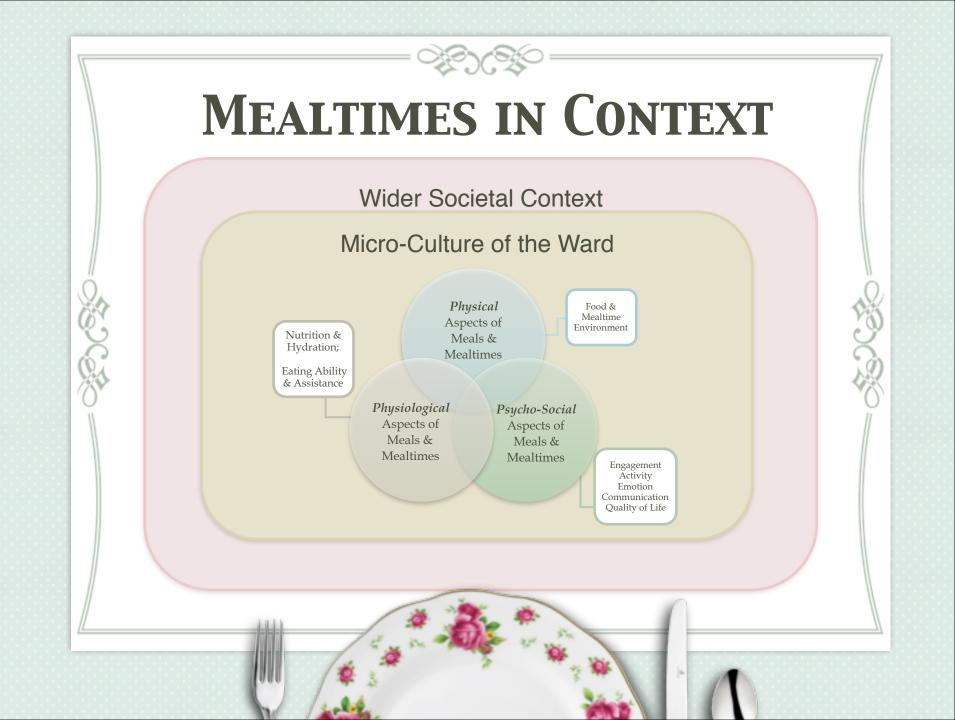
Physical
Aspects of
Mealtimes

Food & Mealtime Environment

Physiological
Aspects of
Mealtimes

Psycho-Social
Aspects of
Mealtimes

Engagement
Activity
Emotion
Communication
Quality of Life



OPERATIONALISING MEALTIMES

Semi-Structured Interviews

Recording Weight/BMI (SU only)

Nutrition & Hydration;

Eating Ability & Assistance

Structured Mealtime Observations (SU only)

Physical
Aspects of
Mealtimes

Food & Mealtime Environment Focussed Ethnographic Observations

Semi-Structured Interviews

Structured Mealtime Observations (SU only)

Staff initiated assessments of nutrition (MNA-SF) and feeding (EdFED) Physiological
Aspects of
Mealtimes

Psycho-Social
Aspects of
Mealtimes

Focussed Ethnographic Observations

Engagement Activity Emotion Communication Quality of Life

Semi-Structured Interviews

'Engagement, Activity and Emotion' Assessment

PARTICIPANTS

25 patients, 13 relatives/ friends and 64 staff (N=102)

SETTING

2 NHS Continuing Care Units (part of the same NHS trust)

PROCEDURE

Stage 1: Pre-Intervention

Stage 2: Intervention

Stage 3: Post-Intervention

Divided across 9-12 months

MEASURES

- Focused Ethnographic Observations of the setting (>300 hours)
- Structured Mealtime Observations (Service Users only; 179 mealtimes)
- Semi-Structured Interviews (where possible including people with dementia; 51 interviewees, many repeat)
- Recording Weight/BMI (SUs only)
- Measuring Activity, Mood and Engagement (SUs only; 1536 obs)
- Staff initiated assessments of nutrition (MNA-SF) and feeding (EdFED)

DESIGN

Action Research with participatory elements (stakeholders co-creating and implementing changes)

WHAT HAS DEMENTIA GOT TO DO WITH EMBODIMENT?

"Through attention to embodiment we have begun to consider the body as <u>a source of</u>

<u>opportunity</u> in relations with and between people with dementia"

(Martin et al, 2013)

WHAT HAVE MEALTIMES GOT TO DO WITH EMBODIMENT?

- ♦ Meals & mealtimes are an important part of people's lives (Larson et al, 2006), but especially for people with dementia (Berg, 2006)
 - ❖ Bodily practice (Fox & Wards, 2008)
 - * Expressions of embodied pleasure (Wiggins, 2002)
 - Pre-reflective expression of selfhood (Sidenvall, 1999)
 - ❖ Time to honour identity (Genoe et al, 2010)
 - Chance to enact independence, as mealtimes rely on habitus (Johansson et al, 2011)
 - * Chance to re-negotiate identities (Hung & Chaudhury, 2011).

WHAT HAVE CC WARDS GOT TO DO WITH EMBODIMENT?

Few Continuing Care (CC) Settings across the UK:

- Under-researched
- ❖ Invisible to the public

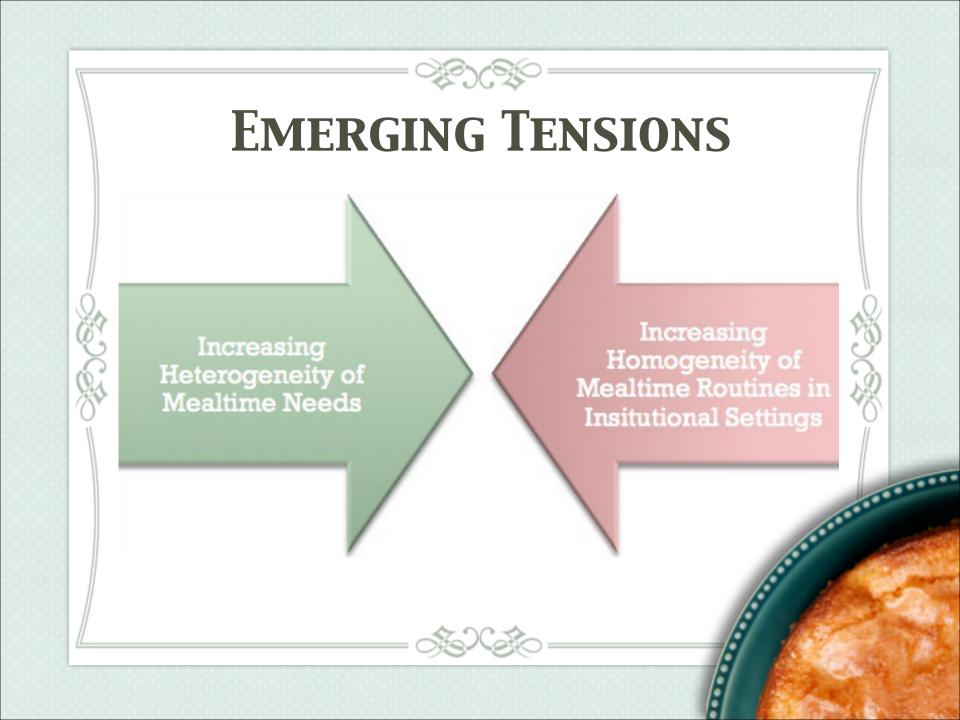
Compared to other forms of dementia care, CC settings are characterised by:

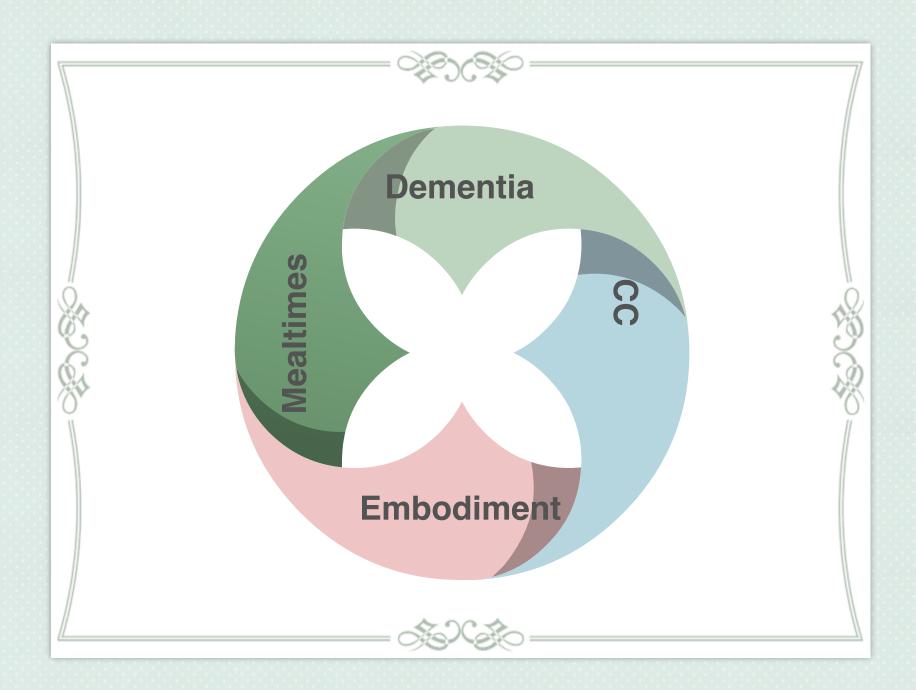
- ❖ (highest) level of need
- complex multiple needs
- hospital environment
- institutional structure and goals

Continuing Care Wards

Care Homes and Nursing Homes

Care in the Community







Unique opportunity to enhance selfhood:

- Chance to connect via a bodily experience
- Affirming identity and relation to others (including social structure and status)
- Stimulating memories via the sensory experience
- Celebrating the body and the mealtime

Ogden Unit **Celebrating Food** Weekly Schedule **Treat Tuesdays** a small buffet and drinks 000 **Cake Wednesdays** tea and cakes or other sweet treats 000 Fruit Thursdays soft fruit & yogurt ~ fruit smoothies Families & friends welcome to join! Also... pancakes or wafles for Sunday Breakfast Sausages and eggs for breakfast - available daily

S2D0403E2: [...] Joan [a former school headmistress] stayed in the office since breakfast. The staff served her lunch on a tray table, but had to leave her to eat independently while assisting patients who needed more input [Joan would rarely allow someone to actively feed her, but was often unable to feed herself due to attention and motor difficulties]. Nina [the ward's administrator] was sitting with her back to Joan, typing. She would, however, look over to Joan from time to time and verbally encourage her to eat. She also occasionally tried to give Joan the spoon or scoop some food on the spoon and leave it for Joan to pick up. None of that seemed to work very well with the main course, and Joan was getting increasingly frustrated, [unintelligibly] verbalising louder and louder. This lasted for over 5 minutes, at which point Nina opened her lunch bag and put some crisps from her packet on Joan's plate. Nina also proceeded to eat the crisps remaining in the bag at the same time facing Joan and asking her to try some. Joan did. She ate almost all the crisps from her plate, independently feeding herself.

S1D1211E3. At teatime Maureen sat down next to Jane, who at that point had not started eating her yogurt. They smiled at one another and seemed to exchange some pleasantries. Jane then pushed her yogurt pot towards Maureen, who happily accepted it and started eating. This was met with disapproval from staff, who loudly told off Maureen for taking Jane's pudding (no one saw Jane give it to Maureen and assumed Maureen had taken it). They forcibly took the yogurt pot from Maureen, who then became upset and attempted to retrieve the yogurt pot from Sally's [HCA] hand. Therefore, she was put in Hold 2 [restraint technique] and escorted to her room. No replacement pudding was offered to Jane and Maureen was too distressed to eat at this point.

S1D2702E3. [...] Staff were busy in the two dining rooms and feeding patients in their rooms, so no one was supervising the foyer or encouraging Walt or Hazel (previous structured observations have shown that both these patients benefitted from verbal prompts and occasional physical prompting, but did not require feeding). During one of her 'visits', Maureen came in with a corned beef sandwich [sliced into 4 triangles] and sat down next to Walt who at that point was not eating from the plate in front of him. She proceeded to pass one of the triangles over to him, which he ate and she continued to eat hers. Often restless, Maureen walked away for a while, but then came back to give Walt another piece of the sandwich, which he ate. They both chatted and smiled and the half of the sandwich was the only food Walt ate that evening.



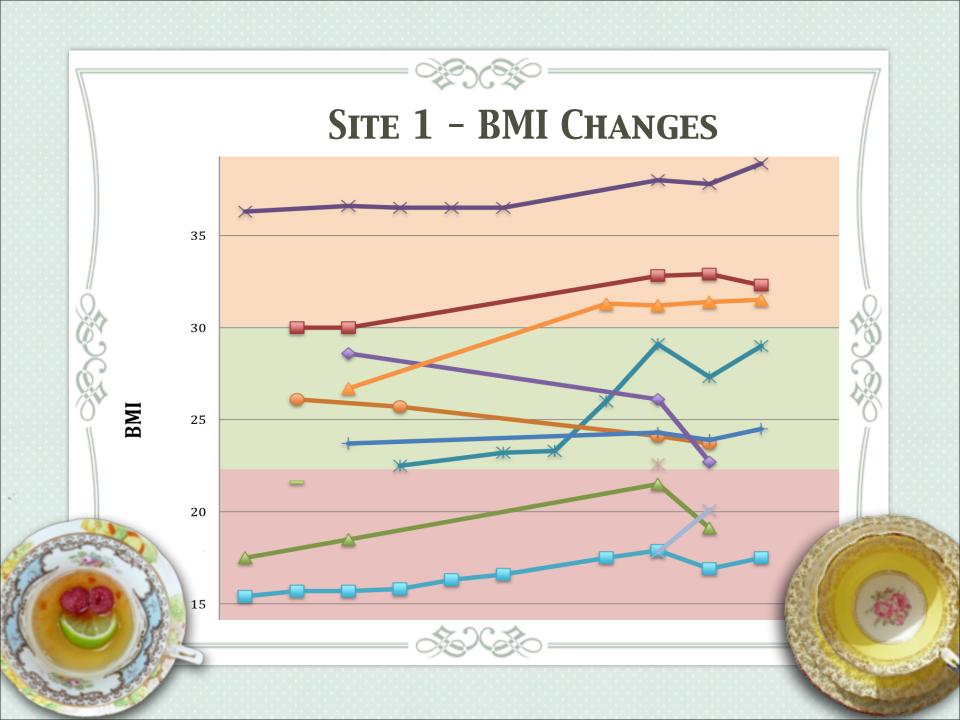
BODIES MADE INVISIBLE

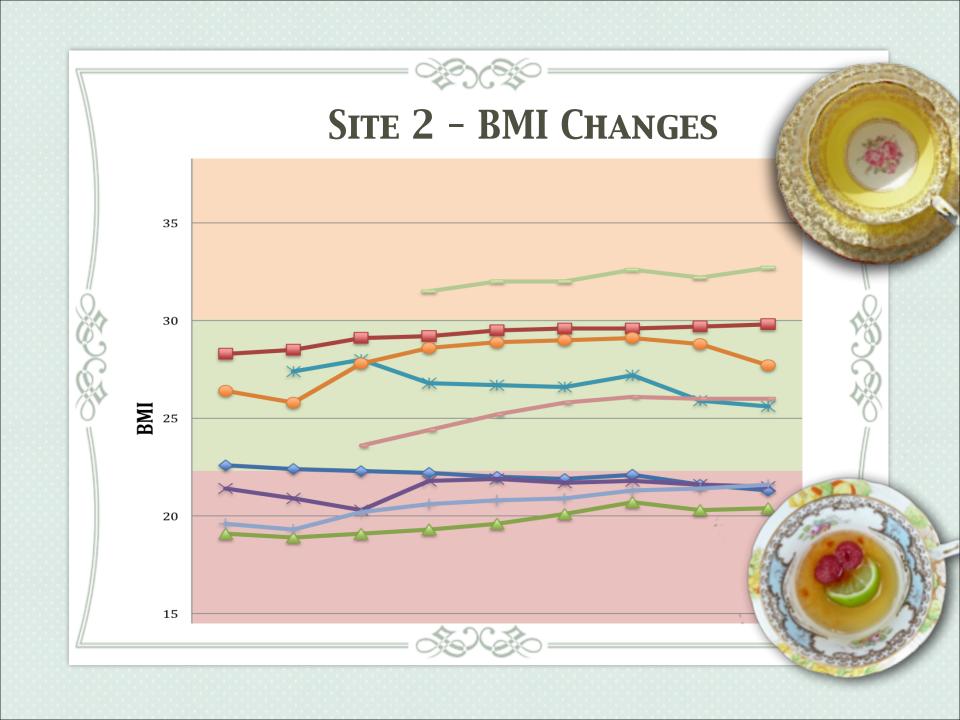
Constructing the body with dementia in institutions:

- "Weight loss is normal for dementia"
- Only overweight people are a 'problem'

Making the body invisible and irrelevant:

- Lack of social opportunities at mealtimes
- Little focus on environment or pleasure







MEALTIME FOCI

Social Needs Sensory Needs

Physiological Needs

Patients / Residents

Focussed primarily on the social side of mealtimes (eating together, sharing food and conversation). Sensory needs also acknowledged, but seen as less important. Physiological needs not mentioned

Relatives

Focussed primarily on sensory needs (tasty food, and pleasant eating environment with appropriate cues) but acknowledge physiological needs, too

Staff

Focussed almost exclusively on nutrition & hydration (the clinical needs around mealtimes)



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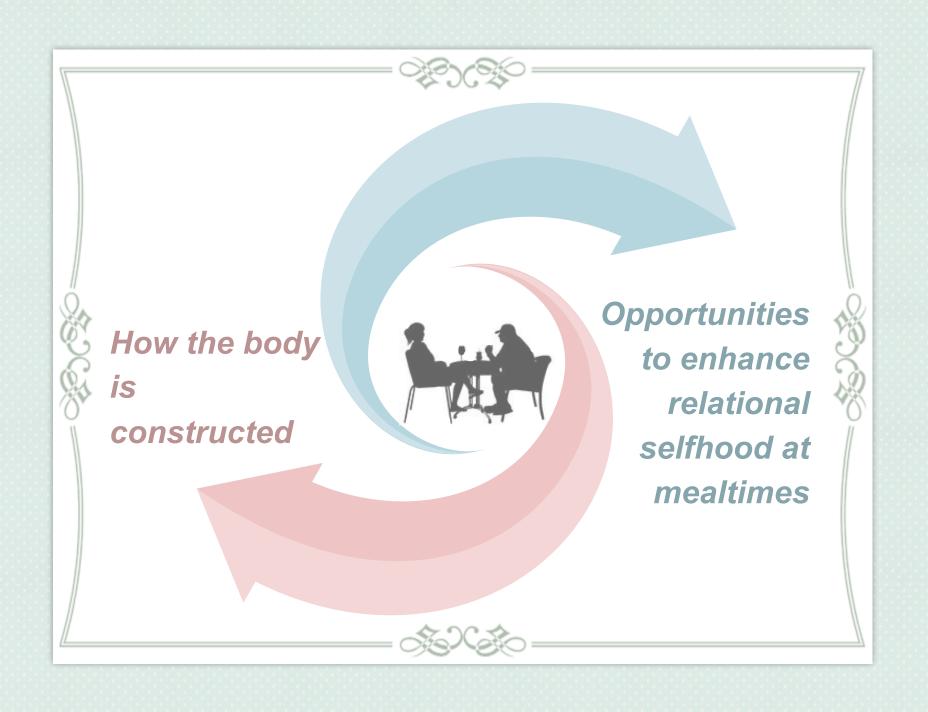
"I don't like eating like this! I want to eat with everyone else"

"Why do they sit me separately? [...] I used to like eating with my family... It was happy... It's not happy now"

[short pause]

"Where's my mum?!" [shouted loudly]

"I'd rather not eat at all than eat like this. Why did they separate me? Why did they sit me away from other people? They made me different!"



So WHAT?

- Dominant discourse of 'nothing left behind' is challenged by notion of embodied selfhood (Kontos et al, 2017)
- ❖ Mealtimes offer unique opportunities to affirm personhood and enhance relationships in dementia, even for people living with advanced dementia
- However, the mind is not the only thing that changes with the advancement of dementia
- ❖To foster embodied approaches in dementia care work should also take place on re-constructing the body with dementia.

To shift the paradigm of dementia from *deficit* to *embodied interconnectedness* we must reframe the 'body with dementia'



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The study has been approved by the Social Care Research Ethics Committee. REC reference: 13/IEC08/0018

This research project is hosted by KMPT and University of Kent, and sponsored by Kent Health







