

# *DEMENTIA CARE: A POSITIVE FUTURE, MAY 2010*

**Capturing the Lived Experiences  
of Care Home Residents with  
Dementia: what's the point?**

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# CONTEXT

- **Over two thirds of the 420,000 people living in care homes in the UK have dementia**
- **Despite this preponderance research that captures their experiences is limited**
- **In part this reflects their liminal status *inside & outside* the care system**
- **As well as the genuine complexity of collecting meaningful data from people whose cognitive & communication skills are limited**
- **Growing body of evidence about the subjective experiences of living with early stage dementia**
- **Also increasingly accepted that people in middle/late stage dementia retain the capacity for emotional expression**

# THE CARE HOME EXPERIENCE

*Two key sources of evidence to date:*

- Practice based work whose core aim is that of improving care - Dementia Care Mapping
- Research that has attempted to capture the nature & dimensions of care home life 'from the inside' or through the eyes of carers
- Predominantly this material is gathered from observational or q'aire based studies which provide valuable insights

*Third emerging source of evidence:*


- Work that focuses on the subjective experience of the resident with dementia is a new addition to the research portfolio

# EVALUATING THE EXPERIENCE OF THE PERSON WITH DEMENTIA


- **Structured observational methods developed specifically for evidencing quality in LT care**
- **Provide an opportunity to include the perspective of the person with dementia**
- **Most widely used dementia specific observational tool is DCM: ‘a serious attempt to take the standpoint of the person with dementia, using a combination of empathy & observational skill’ (Kitwood, 1997)**
- **Video & digital recordings have also been used in care settings to elicit insights into life in a care home**



## **EVALUATING THE EXPERIENCE OF THE PERSON WITH DEMENTIA (2)**

- Extent to which selfhood & identity are preserved in people with dementia is a key focus of observational studies**
  - Evidence suggests that although the self is affected by dementia, manifestations of selfhood persist**
  - Research also identifies issues of loss, communication difficulties, frustration & sadness amongst residents with lack of meaningful occupation**
  - Minimal levels of well being are widely noted in care home studies esp. for those with the greatest levels of need**
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# SUBJECTIVE EXPERIENCE OF THE PERSON WITH DEMENTIA

- Recent attempts have been made to explore the subjective experiences of care homes residents with dementia
  - Seminal study by Clare et al (2008) provides an interpretative phenomenological account of the psychological experience of living in a home
  - Thematic account highlights a number of interrelated experiences:
    - Daily experiences shaped by losses resulting from dementia; distressing thoughts & feelings
    - Psychological impact of 'being in a home' was associated with a sense of uncertainty, lack of control & limited self determination
    - Feelings compounded by multiple experiences of loss - lost abilities, lost memories & lost identity
    - Feelings of 'being alone' & or 'being lost' was also a dominant experience
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# **SUBJECTIVE EXPERIENCE OF THE PERSON WITH DEMENTIA (2)**

- BUT... residents also emerged as ‘agents actively seeking to cope with their situation’**
- Many found ways to contribute & focus on positive aspects of home life e.g. supportive relationships**
- These are pivotal to maintaining well being**
- Their absence contributed to feelings of distress & alienation**

# SUBJECTIVE EXPERIENCE OF THE PERSON WITH DEMENTIA (3)

- Although participants displayed constructive ways to cope, the effects of dementia related changes *alongside* institutional context placed limitations on expression of personal agency
- Consequently some residents experienced frustration, anger & boredom
- Lack of freedom & independence was experienced by some as 'restrictive'
- Communal living could also give rise to considerable confusion

## KEY THEMES: CLARE ET AL'S STUDY (2008)

- ***Nothing's right*** - isolation, alienation, lack of choice, lack of control, fear, worthlessness
- ***I'll manage*** - making the best of things, valuing contacts and friendships, finding ways of continuing to be useful, being accepted as you are, having a friend in the home, having links with relatives/family, acknowledgment of getting older
- ***I still am somebody*** - part of coping, affirming one's sense of identity, managing well despite limitations
- ***It drives me mad*** - situation, confined, wanting more independence, boredom, lack of activity, annoying behaviour of other residents, uncertainty, fear, irritation



# IMPLICATIONS FOR PRACTICE


- **Understanding the subjective experience of people with dementia living in a home is a fundamental dimension of improving practice & quality of life**
- **Key issues are:**
  - **Embedding person centred values in care home culture**
  - **Recognising crucial role of developing meaningful relationships between staff & residents**
  - **Emphasis on effective communication**
- **Also addressing practical & therapeutic deficits:**
  - **Extending levels of engagement by offering meaningful activities**
  - **Supporting continued expression of agency & autonomy**
  - **Managing the difficult & negative emotions experienced by residents**
  - **Supporting role identity**
  - **Awareness of the challenges of a semi-public life**




## IMPLICATIONS FOR PRACTICE (2)

- **Preservation of self & identity appears possible even amongst those with advanced dementia**
- **Maintenance of previous relationships with friends/family is key to providing biographical continuity**
- **Moving into a home causes ‘biographical disruption’ - tends to impact negatively on users’ sense of self & relationships**
- **The provision of person centred care in this context is paramount - knowing the individual, their wishes & preference, & building up meaningful relationships**

# IMPLICATIONS FOR PRACTICE (3)

- **Key elements of good quality care:**
    - **Recognition of residents' emotional & social needs**
    - **Spending time engaging residents 'in conversation'**
    - **Finding ways to communicate**
    - **Staff being attentive, actively listening, & observation of non-verbal signs**
    - **Support users' coping strategies**
  - **For staff meaningful communication is key dimension of job satisfaction**
  - **Needs to be core component - for benefits of residents & staff - of dementia care training**
  - **Plus care homes need to ensure staff have time & expertise to maintain r'ships with users**
  - **Those homes that provide good quality care have: leadership, positive ethos, staff training & ongoing support**
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# CONCLUSION

- **A person with dementia in a care home faces a set of enormous challenges**
  - **Declining cognitive powers + staff who often know little about them**
  - **Encouraged to focus on technical aspects of care rather than emotional or social well being**
  - **Voices of residents easy to overlook**
  - **Understanding more about the experience of living with dementia in a care home is critical to enhancing quality of life & care**
  - **Research in this complex & 'hidden world' is emerging as making a key contribution to this discourse: more is needed!**
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