

How can I tell you what's going on here?

The development of PIECE-Dem: An observational framework focussing on the perspective of residents with advanced dementia living in care homes.

Background:

People with advanced dementia face particular challenges in not being able to tell anyone directly about their experiences, especially if care is poor. They are also more likely to be vulnerable to the risk of abuse, neglect and loss of dignity.

Whilst it is recognised that much can be gained by interviews and focus groups, the perspective of those with significant communication problems is likely to be under-represented. PIECE-Dem was developed to capture their experience.

PIECE-Dem stands for:

Person
Interaction
Environment
Care **E**xperience
in **D**ementia

About the Association for Dementia Studies:

The Association for Dementia Studies is an active research and education centre. Our multi-professional team are experts in the field of person-centred dementia care and support.

Through research, education, consultancy and scholarship, we make a cutting-edge contribution to building evidence-based practical ways of working with people living with dementia and their families that enables them to live well.



Aims of the research:

We aimed to develop a robust and sensitive tool that:

- Focused on the experience of people with advanced dementia to ensure that their perspective is included in research.
- Could capture both positive and negative experiences of care which could help differentiate between care environments where abuse, neglect and loss of dignity were more or less likely to occur.
- Could be used both by researchers and practitioners with minimal training to assess the experience of those with very limited or fluctuating cognitive abilities.
- Focused specifically on observable signs of abuse and neglect or risk factors associated with this.

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<https://www.worc.ac.uk/discover/dementia-piece-dem.html>

Developing PIECE-Dem:

13 in-depth interviews and 5 focus groups were undertaken with experts by experience including professionals, whistleblowers, family members whose loved ones had been abused in care, and people living with dementia. Thematic analysis identified key themes from which a pilot observational framework was developed.

The observational tool was developed in practice in 7 care homes in 11 successive trials. After each trial the observation results and researcher reflections about the process and experience of observation were used iteratively to inform further development of the tool and the underpinning theoretical framework.

Repeat visits to 3 care homes were completed to carry out inter-rater reliability, which showed a high level of concordance between researchers.

How PIECE-DEM is used:

One researcher observes two participants, spending time alternately with each in 15-minute blocks for 2 hours, after which the observations are summarised.

The researcher observes the participants' experiences of the world around them and makes a written record at one-minute intervals of their levels of engagement, interactions that occur and how their immediate environment appears to be impacting upon them.

Implications for policy and practice:

PIECE-Dem provides a structures means of including the perspective of people with advanced dementia in research into the quality of care.

It has potential to be a useful tool for those with responsibility in regulating, inspecting or monitoring care practice.

It provides further insight into the experience of people with advanced dementia in care, recognising that challenges tend to be institutional rather than with individuals.

Who is observed:

Four residents are selected to be observed in detail. As well as dementia, the selected residents have high levels of need and characteristics which mean they are potentially most at risk of neglectful or abusive practice. Residents are not observed if they have a history of paranoia, are newly admitted, or have unstable mental or physical health. Anyone who appears uncomfortable with the researcher's presence is excluded from the observation process.

Where to use PIECE-Dem:

Observations generally occur in public areas. Intimate care activities are not directly observed, but how residents are escorted to the bathroom following an episode of incontinence, how they appear following intimate care delivery, or how they are helped to eat a meal will often be very telling. Observation periods include times of high demand for staff interventions and times when there is a high level of need for personal care, as well as reflecting the resident's routine and level of activity.

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