

Implications for policy and practice

PIECE-dem:

- Provides a structured means of including the perspective of people with advanced dementia in research into the quality of care in care homes and other long-term care settings.
- Has potential to be a useful tool for those with responsibility in regulating, inspecting or monitoring care practice.
- Provides further insight into the experience of people with advanced dementia in care, recognising that the challenges people face tend to be institutional rather than in individual residents or staff.

It is planned to adapt the manual for use by care practitioners as a practice development tool to improve their care of people with dementia and high dependency needs.

PANICOA

This study is part of the PANICOA (Prevention of Abuse and Neglect in the Institutional Care of Older Adults) Research Initiative. This is joint-funded between the Department of Health and Comic Relief to enhance the dignity and quality of care of older people living in institutional settings. Its aims are to:

- Increase knowledge of the extent of abuse and neglect of older people in institutional care
- Improve understanding of the context, causes and impact of abuse, neglect and/or loss of dignity in institutional settings, from the perspective of all those centrally involved;
- Provide the evidence to help develop more effective ways of preventing, identifying and responding to abusive, neglectful or exploitative relationships in institutional settings.

PIECE-dem will be used in the final PANICOA study (CHOICE) as setting the focus for in-depth qualitative ethnographic observation and interviews examining organisational culture in relation to good care or mistreatment.

DISCLAIMER: The views expressed in this report are those of the authors and not necessarily those of the funders.

Further information

This research was undertaken by the Association for Dementia Studies at the University of Worcester. The research team included Professor Dawn Brooker, Jenny La Fontaine, Dr Kay De Vries, Tom Porter, and Dr Claire Surr (Bradford Dementia Group).

Further information about PIECE-dem can be found on our website.

It is anticipated that the manual will be downloadable from the website. It is planned that we will provide a number of training events for researchers and practitioners who wish to use this in practice. Please see our website for details.

<http://www.worcester.ac.uk/discover/association-for-dementia-studies.html>



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.

Introduction

People with advanced dementia face particular challenges in not being able to tell anyone directly about their experiences, particularly 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.

Key messages

PIECE-dem is an observational process that appears to be sensitive enough to pick up both neglectful and supportive practice.

In our observations we saw little that could be described as deliberately abusive. However, much was certainly neglectful of people's physical, psychological and spiritual needs.

Using PIECE-dem, we also observed people with advanced dementia who were well supported, who experienced joy and who were engaged with the world around them in a way that supported their physical and psychological needs.

In our feedback sessions with staff, we witnessed an enormous amount of care and concern on their part to provide good quality care. We also found lack of knowledge about the life histories of the people we observed and a lack of knowledge and skills about how to care for people with advanced dementia.

Our observations suggest strongly that neglectful or supportive practice is linked to the qualities in the care culture rather than a response to the characteristics of individual residents.

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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Methods

13 in-depth interviews and 5 focus groups were undertaken with experts by experience including professionals, "whistle-blowers", family members whose loved ones have been abused in care and people living with dementia. Participants discussed what signs would make them concerned or reassured about the culture of a care home regarding observing:

1. The Person with advanced dementia;
2. Interactions – between staff and residents;
3. General environment.

We used thematic analysis to identify key themes. From this we developed a pilot observational framework.

The observational tool was developed in practice in 7 care homes in 11 successive trials. Two researchers (4 observers in all) observed in each care home. Inclusion criteria for participants included people with severe dementia with a variety of needs around mobility, physical health and sensory impairments. Standardised measures suggested that the participants' quality of life was judged as poor, that they were highly dependent in terms of requiring support and that they had a significant degree of dementia.

After each trial, the results of the observation, the researcher reflections upon the process and experience of observation and the earlier focus groups and interviews were used iteratively to inform the further development of the observational process, and the underpinning theoretical frame.

PIECE-dem was finalised after seven care home trials. Repeat visits to three homes were completed to carry out initial inter-rater reliability which showed a high level of concordance between researchers.

The content of PIECE-dem

A manualised tool, the PIECE-dem, has been built as a result of this research. This stands for:

Person
Interaction
Environment
Care Experience
in Dementia

One researcher observes two participants, spending time alternately with each in 15-minute blocks over a two-day period and making a written recording at approximately one-minute intervals. PIECE-dem is usually used from 1pm-9pm on day one and 8am-1pm on day two, which enables the researcher to observe how people change over time and how different staff and routines impact upon the experience for each participant. The researcher observes the participants' experiences of the world around them, including recording levels of engagement, the interactions that occur with the participant and how their immediate environment appears to be impacting upon them.

Observations are summarised every 2-3 hours on behalf of each participant. This summarises:

- Actions (and their possible intention) that were observed/expressed by the **Person** with dementia;
- Direct actions of others as they relate to the participant. This includes the nature of the **Interaction** and how this appeared to be experienced by the person with dementia;
- The immediate physical and psycho-social **Environment** surrounding the participant.

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 have characteristics which mean they are potentially most at risk of neglectful or abusive practice, for example those who are least able to communicate. We don't observe residents who have a history of paranoia, who are newly admitted or those whose mental and physical health is particularly unstable. Anyone who appears uncomfortable with the researcher's presence is excluded from the research. Processes around the ethical conduct of researchers using PIECE-dem are included in the manual to ensure that participants are at ease with the researcher's presence during observation. If this cannot be achieved, then the observations are discontinued.

Where we 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 people are helped to eat a meal will often be very telling about how even more intimate care might be given. 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.

Feedback to staff

The researchers discuss their observations with the key worker and manager. We highlight different situations where the participant is in states of relative well- and ill-being because of interaction or environment factors. In the majority of the pilot sites, the feedback was well received. However, in two of the care homes where the care practice was less positive, there was a noticeable reticence from some staff to be present in areas where observation was taking place and, subsequently, to hear feedback which was challenging to their perception and understanding of their residents' needs

The emotional impact of observing

During the experience of developing PIECE-dem we found ourselves experiencing a powerful range of emotional responses. These experiences were pertinent to our position as non participant observers where we were obliged to remain 'distant' (unless we witnessed practice that put the person with dementia at risk and required immediate intervention). During PIECE-dem we all encountered situations of recognising that the person with dementia was experiencing a state of ill-being or discomfort that manifested at a subtle level but were overtly clear to us due to the closeness of our observations. This produced an emotional and moral dilemma for us in attempting to maintain the 'researcher' stance whilst struggling with the imperative to respond to their need. Alongside this was the knowledge that our position allowed us to witness this subtle distress and bring it to the attention of those who could alleviate it on a regular basis.