CPA Findings

How can the care experience of older people in care homes be improved: findings from five PANICOA studies.

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Centre for Policy on Ageing

The Centre for Policy on Ageing, established in 1947 by the Nuffield Foundation, has a long and distinguished record as an independent charity promoting the interests of older people through research, policy analysis and the dissemination of information. The Centre aims to raise awareness of issues around ageing, influence the development of policies to enable older people to live their lives as they choose, and to support good practice. CPA's overarching focus since its inception has been on empowering older people to shape their own lives and the services they receive. The fundamental touchstone of its approach is to discover and advocate what older people themselves want and need.

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The PANICOA programme, funded by the Department of Health and Comic Relief, commissioned a series of studies, including five which focussed on the care experience of older people in care homes, seeking ways to improve care and minimise the chances of abuse and neglect.

The Centre for Policy on Ageing has drawn together key messages from the five studies with the aim of developing a dissemination strategy to enhance the care of older people.

The studies themselves are listed in Appendix 1 and are available on the PANICOA website http://www.panicoa.org.uk/studies

Key findings from the studies

While noting the challenges faced by care home on the ground, the Panicoa studies drew out the importance of person-centred care; relationships and participation; organisation and culture and freedom to speak out and voice concerns as important elements in the provision of good care, free from the risk of abuse and neglect. The studies also noted the importance of the culturally competent care of ethnic minority residents and the need for a special awareness when caring for residents with dementia.

A positive view

The five PANICOA reports, in general presented a positive view of the care they had observed presenting an overall picture of a successful effort, on the part of care homes, to provide sensitive resident-centred care in the face of a number of challenges. The studies observed many cases of good management and good practice with a number of transferrable examples of good care.

The absence of abuse and neglect in the institutional care of older adults is inextricably intertwined with all other aspects of good care.

Challenges at ground level

Care home staff and managers are seen as facing a number of challenges on the ground.

- **Getting the 'basics' right**
  The way in which the basics of life, food, drink and toileting, are provided is a fundamental aspect of good care home care. These basic elements, which provide the bedrock of good care, have to be 'got right', even while recognising that there is more to good care than providing the basics. For residents themselves, the three most important elements are safety and security, toileting and relationships.

- **Changing care needs**
  The care home population is changing with increasingly dependent residents, with higher levels of dementia and increased frailty, staying for a shorter period of time towards the end of their life. This changing 'demographic' places increased demands on care home managers and staff leading to a more stressful environment. The studies noted that care homes also face difficulty in responding to the changing needs of existing residents. As a resident's care needs increase some homes may not be able to cope with the higher levels of dependency but may not want to ask the resident to leave, both for financial reasons and so as not to upset the resident.

- **Care homes are under-resourced and staff under-valued**
  A common theme emerging from the reports is that care home managers and staff see their

care homes as under-staffed and under-resourced with staff who are under-valued. Organisational systems are restrained by the level of funding per resident which was universally reported as falling short of the true cost of meeting residents' needs.

- **Staff under stress**
  Although, on average, care home staff are no more psychologically distressed than the general public, perceived workload is a major source of stress. Staff may adopt a distancing coping strategy, adopting a more detached attitude and show a lack of empathy and involvement with residents to avoid 'burn-out', physical and emotional exhaustion and demoralisation which itself involves negative job attitudes and a loss of concern for clients. Many staff show signs of emotional exhaustion and a moderate or low sense of personal accomplishment while more positive approaches by staff to ageing and dementia care are associated with less emotional exhaustion, greater job satisfaction and a greater sense of mastery and personal accomplishment

Person-centred care

All the studies agree that person-centred care, in which the resident is seen as an individual rather than the object of a caring process, will produce the best care outcomes.

- **Homely care**
  It is important that care homes present a 'homely' rather than 'institutional' atmosphere with an emphasis on person-centred care rather than task based routines. Staff need to be aware of residents as individuals with individual needs and sensitivities.

- **What matters to residents**
  For residents, issues of safety and security are of fundamental importance, closely followed by issues of toileting and the need for meaningful relationships.

    - Issues of safety and security included the fear of having to leave the care home for financial reasons, fears of other residents' behaviour and fears of staff behaviour.
    - Despite the organisational attention paid to it, toileting is a major area of concern and anxiety to residents. Residents may be very aware of the competing demands on staff time but soiling oneself will be, to some residents, the ultimate indignity.
    - Meaningful relationships with other residents and staff was an important issue including not being talked down to by staff and, for some, the importance of maintaining relationships with family and friends outside the care home.

- **Effective change**
  A small, person-centred change to practice can make a big difference to residents.
  For example
    - Although, at busy times, it may not be possible to attend to residents' needs immediately, a quick response indicating how long it will be before the need can be dealt with, can put a resident at ease.

Relationships and participation

Residents place a high value on their relationships with staff, relatives and other residents. A common theme in the studies is the importance of meaningful relationships between relatives and residents and care home staff and management.

- Residents seek the warmth and degree of attention from staff that they would get from friends or family. The contribution that relatives and residents can make to ideas about the organisation of the home should also be recognised, and a willingness to help with day-to-day activities, should be welcomed.

- Some residents want to be involved in the working activity of the home and this should also be welcomed and facilitated wherever possible

- Relatives could be involved as volunteer support in the care home and relatives are often attuned to residents' needs and should be encouraged and listened to as monitors of standards within the home

- On the negative side, care home staff need to be alert to the risk of abuse by relatives

Organisation and culture

The residents' care experience and staff work experience are very much affected by the organisation and culture of the home. A strong positive culture incorporates assumptions, values and norms consistent with and underpinning good care. Negative organisational factors can prevent 'good' care by a 'good' person.

A culture that supports high quality care includes

- Active mediation of external pressures
- Empowering and present leadership
- Shared understanding of vision, purpose and practice
- Sense of 'connectedness' within the home

Elements seen as important in the organisation of good care include

- **Effective leadership and supervision**
  Effective leadership includes unity of vision purpose and practice and an empowering and distributed leadership
- **Teamwork**
  Teamwork includes human relationships, staff friendliness and the relationship between carers and residents. Teamwork can be affected by tensions between staff groups.
- **Routines and work based norms**
  Although work routines are subject to work-pressures and strains it is important to avoid the objectification of residents by staff
- **Openness and relatives participation**
  A care home confident in its approach to care will be inclusive and wish to involve residents and relatives
- **Meeting residents needs and skilful practice**
  Attention has to be paid to the proper provision of fundamental care and sensitivity to the maintenance of dignity and individuality

    - Eating and drinking – offering a choice of food, making time
    - Toileting – recognising and responding promptly to signs of need
    - Medication (including the dilemma of balancing the residents wishes not to take medication against a doctor's prescription for the health of the resident)
    - The importance of providing social interaction and activities.
- **Care quality and responding to mistreatment**
  Effective structures have to be in place for monitoring and accountability and the formal and informal resolution of issues
- **Being resourceful**
  There is a need to overcome the difficulty of adopting a business strategy to cope with the cost of care while providing equity and fairness and a career progression for staff
- **Feeling of 'being at home'**
  A sense of 'home' in communal and individual living, choice and decision making including the presence of personal effects including toiletries

Organisational factors particularly relevant to enabling or undermining responsive, person-centred care include

- The frequency and extent of organisational change
- Low staffing levels
- A lack of continuity of staff
- Unclear communication of expected standards
- Inadequate funding
- The prevalence of rigid routines
- High levels of bureaucratic process and restrictive organisational rules

Freedom to speak out or voice concerns

To deal effectively with problems that might arise in care homes, residents, relatives and staff need to feel safe to raise concerns and issues without the fear of repercussions. A 'no blame' culture for staff may help in this respect.

Within the Panicoa reports, in several homes where interviews took place, staff said they had not witnessed abuse or neglect in the care home in which they were currently working but had witnessed it in care homes in which they had previously worked. This may indicate that staff are reluctant to highlight problems in their current work place or that a lifetime of previous experience, because of it very length, gives rise to a greater chance of observing poor practice.

Culturally competent care

Population projections indicate a likely substantial growth in the ethnic diversity of care home residents, particularly in London and the other major conurbations of England and Wales.

Many of the aspects of good care for older people in care homes, with and without dementia, from black and minority ethnic communities, are the same as for all other residents. The Panicoa studies emphasised the importance of communication, attitudes and relationships and culturally competent care.

For BME residents, communication is important and it is advantageous to be able to talk with residents in their own first language, whenever possible. A person's language is part of their

personal identity but good communication is more than just the use of a particular language. Good communication is essential and has to be achieved, without good language skills, where the use of language is limited either by linguistic differences or by dementia.

Attitudes and relationships are very important. Not only relationships between staff and residents but between individual residents, particularly in a multi-cultural environment.
Relationships need to be carefully managed to allow residents to spend time with those whose company they prefer while avoiding isolating individuals, cultural stereotyping or racism. The layout and facilities of the home are instrumental in managing relationships, for example the use of more than one lounge. Staff may also be drawn from black and minority ethnic groups and there is a risk of cultural stereotyping and racism not only from staff but also towards staff as well as between residents. Some staff feel that some residents from some cultures may have a tendency to see them as servants.

Culturally competent care involves a knowledge and awareness of cultural diversity and the views and practices of the individual religions and cultures of residents so that care may be offered in an appropriate way. Training in cultural competence should be part of staff training.

Handling cultural diversity is complex and may give rise to difficult dilemmas. Older people in care homes will reflect the attitudes and experiences of the wider society from which they are drawn. This may range from the ties, parochialism and tensions of a close-knit ethnic community causing issues with gossip to an acute sensitivity to perceived racism based on actual experiences as a migrant within the broader community.

Caring for residents with dementia

Many, if not all, of the elements of good care for a resident with dementia or high support needs living in a care homes are applicable to all residents. The difference is that people with dementia are more vulnerable and therefore more at risk of abuse or neglect, while at the same time being less able to articulate their fears and experiences. This places an obligation on the part of relatives and care home staff and management to be particularly watchful of the care and experiences of an older resident with dementia.

The PIECE-Dem observational tool, developed as part of the Panicoa studies, provides a watch-list to monitor the care, and understand the experiences, of an older resident with dementia. It is based on three elements: the **person** with dementia; **interaction** between the resident and staff and the **environment** of the care home.

Observable aspects of the person include *physical appearance*, *cleanliness* and *overt signs of distress*. Aspects of the interaction with staff include *inclusiveness* and *warmth* or *control* and *disrespect.* Aspects of the care home environment include the *general appearance*, *smells*, *noise*, the *presence or lack of stimulation* and the *use of protective technology*. A fuller list is provided in Appendix 2.

Combatting abuse and neglect

The Panicoa studies had been asked to focus on the risk of abuse and neglect in institutional care. Incidents of abuse and neglect in care homes are thankfully rare but tend to be examined at the level of the individuals involved rather than seeking an explanation, at the level of organisational dynamics, of how and why mistreatment may occur. There is, however, a need to not only be tough on abuse but also tough on the causes of abuse.

The organisational features observed to have been associated with mistreatment can be subdivided into five groups: *organisational infrastructure*; *management and procedures*; *skill mix, training and members of staff*; *characteristics of the resident population* and *other (combined) factors*.

Organisation infrastructure includes *run-down establishments*; *cramped conditions*; *poor hygiene* and *unchanged bed linen*. Management and procedures includes *poor management or leadership*; *failure to take action following previous investigations* and *inadequate policies and procedures*. Skill-mix, training and members of staff includes *difficult shift patterns*; *long hours of work*; *low pay*; *poor training*; *low status* and *poor English language capability*. Characteristics of the resident population include *high levels of dependency*, *cognitive impairment* or *dementia*. Other factors include *poor communication between staff and residents*; the *institutionalisation of staff* and *entrenched routines.* A fuller listing is provided in Appendix 3.

The interplay between the five elements: organisational infrastructure; management and procedures; skills mix, training and numbers of staff; resident population and other (combined) factors is complex and often context-specific, the peculiar combination of factors determining the quality of care in a particular instance. This makes induction and generalisation, drawing wider lessons from particular cases, particularly challenging.

Where next

The PANICOA reports imply the need for care homes to be embedded in their local community and to provide a 'home' for residents. The pressure on resources, homeliness and community involvement issues might all be addressed by an increased willingness to involve relatives as volunteers in the day-to-day running of the care home, although the organisational changes required to allow this to happen should not be underestimated.

The reports highlight the importance of organisational structures and culture in the provision of good care, emphasising the importance of a unity of vision, purpose and practice throughout the organisation, perhaps through distributed leadership.

In the future, care home management and staff may find themselves increasingly under pressure from changing regulations, staff shortages and under-funding while, at the same time, the care needs of care home residents increases as the proportion of care home residents with dementia and high support needs rises.

Care home populations will become increasingly ethnically diverse, particularly in the major conurbations of England and Wales, increasing the need for 'culturally competent' care to avoid inappropriate or insensitive treatment which might be considered abusive or neglectful.

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Appendix 1

PANICOA (Preventing the Abuse and Neglect in Institutional Care of Older Adults) is a programme jointly funded by the Department of Health and Comic Relief.

The five PANICOA Reports

The five PANICOA studies were

- **How can I tell you what's going on here?** The Development of PIECE-dem: An observational framework to bring to light the perspective of residents with advanced dementia living in care homes.
  Professor Dawn Brooker, Jenny La Fontaine, Dr Kay De Vries, Tom Porter, Dr Claire Surr

- **Dignity and respect in residential care**: issues for black and minority ethnic groups
  Alison Bowes, Ghizala Avan and Sherry Macintosh

- **PEACH –Promoting Excellence in All Care Homes**
  Win Tadd, Robert Woods, Martin O'Neill, Gill Windle, Simon Read, Diane Seddon, Charlotte Hall and Tony Bayer
  exploring the needs, knowledge and practices of the care home work force

- **Organizational dynamics of respect and elder care**
  Anne Killett, Diane Burns, Paula Hyde, Fiona Poland, Richard Gray, Andrea Kenkmann
  looking at the organisational dynamics (interactions between structures, staff and residents) associated with good care

- **CHOICE – Care Home Organisations Implementing Cultures for Excellence**
  Anne Killett, University of East Anglia, and colleagues
  which uses the PIECE-Dem tool, highlighting key practices and organisation features implicated in the positive and negative experiences of residents.

Appendix 2

Watch-list from the PIECE-Dem observational tool

PIECE-Dem stands for Person; Interaction; Environment and Care Experience in Dementia referring to three key aspects and indicators of the care home experience of a person with dementia.

Person (the individual with dementia)

- **Physical appearance**
  Cleanliness, tidiness and the absence of injuries
  Overt signs of distress
  Extremes of behaviour, high levels of challenging behaviour, harm to other residents, unattended distress and calls for help
  Signs of agitation and anxiety
  watchfulness, wariness, tension or fearfulness particularly around certain people
  Withdrawn, passive or disengaged behaviour

Interaction (between staff and resident)

- (negative indicators)
  Depersonalising behaviour
  not acknowledging individuality, not explaining actions or interventions, not providing or acknowledging residents' choices, being unaware of a resident's needs or history, outpacing a resident and task focused rather than person focused interaction;
  Ignoring residents
  talking over the resident, no communication during an intervention, ignoring resident's requests and not attending to distress or withdrawn behaviour
  Control by staff
  verbal and non-verbal intimidation, manipulation or use of power by staff, discouraging freedom or giving orders rather than choices
  Showing overt disrespect
  the use of inappropriate terms by staff, expressing negative emotions towards the resident or labelling and objectifying residents.
- (Positive indicators)
  Personal identity
  individualised activities and knowledge of the resident as an individual
  Inclusiveness
  appropriate communication during interventions and interaction with staff
  Supportiveness
  equality within interactions, support in eating, supporting choice, distress and challenging behaviour skilfully handled
  Warmth
  attentiveness, patience, being focussed on well-being and showing warmth in interactions including appropriate physical contact.

Environment

- (negative indicators)
  a general appearance of the home not being cared for
  bad smells, particularly of urine, poor decoration and a poor state of cleanliness
  Restrictions on freedom
  restrictions on movement, furniture used as a restraint, privacy not provided for, locked doors, no selection of TV / Radio and facilities available but not used
  Impersonal Environment
  too much noise, inappropriate TV programmes
  Lack of stimulation
  an absence of the resident's own personal effects including items to maintain personal hygiene.
- (positive indicators)
  Stimulating Environment
  opportunities to engage with personal object and the world in general and to take part in meaningful activity;
  Enabling Environment
  the integration of staff and residents, the use of sensors and other protective technology, the facilitation of autonomy and freedom, a lack of clutter with comfortable places to sit but with space to move about

Appendix 3

Organisational features associated with mistreatment

Organisational infrastructure
Run-down establishments; cramped conditions; overcrowding of residents; lack or (or unused) equipment; generally poor physical environment; poor catering and food hygiene issues; unchanged bed linen; strong odours of urine/faeces; lack of privacy with open bathing, toileting and washing

Management and procedures
Poor management or leadership; overly bureaucratic and instructive management styles; failure to take action following the outcome of previous investigations; inadequate policies and procedures on complaints, protection, restraint, incontinence, medication and palliative care; unclear lines of accountability; absence of supervision and monitoring of services and staff; absence of staff appraisal and support; poor judgement in recruitment; poor work regimes including shift patterns and rigid routines and regimen

Skill mix, training and members of staff
Inadequate staffing levels and staff shortages; inadequate staff mix and level of competency; lack of awareness of staff to residents' needs; use of mandatory overtime; long hours; high workload and workload difficulty; poor pay; poor or absence of training; problems of work organisation including job design and relations between staff; lack of team working, staff factions; high turnover and use of short term temporary staff.
Individual staff characteristics include: increased alcohol consumption and dependency; past experiences of childhood abuse; high anxiety scores; negative attitudes towards residents; poor English language capability; a low sense of impact or control over work situation; lack of professional status and development; conformity; low morale.

Characteristics of the resident population
High levels of dependency; cognitive impairment or dementia; aggressive or uncooperative behaviour.

An increase in the proportion of high dependency residents can lead to problems in delivering respectful care.

Indicators of potential mistreatment include unexplained injuries or bruising in unexpected places; dramatic weight loss and malnutrition; dehydration; untreated or poorly treated pressure ulcers; over sedation and unexpected or unexplained death. Residents in cases of mistreatment often have a low level of awareness of how to exercise their rights to independence.

Quickly changing levels of need or a concentration of individuals with high support needs can destabilise the care provision in a home but this has to be balanced against the stress to residents having to leave a home that cannot provide the required support.

Other (combined) factors
Poor communication between staff and residents; the institutionalisation of staff and staff closed off to the possibility of change and development; entrenched routines lead to the depersonalisation and objectification of residents; may be associated with isolation with few visits by outsiders, including management.

Uncertainty, including cut backs in finances and staff, the imposition of targets, reduction of support and the threat of closure are also commonly associated with mistreatment.

All organisational features are restrained by the levels of funding per resident which were universally reported as falling short of the true cost of meeting residents' needs.