CPA Report

PANICOA - A small study to support the development of a dissemination strategy of key findings and recommendations in the care home sector

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Centre for Policy on Ageing

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1. Introduction

In order to inform the development of a meaningful dissemination strategy for the PANICOA programme, and to help derive practical benefits of value to care homes, from the findings of the research studies, it was decided that the Centre for Policy on Ageing and *My* Home Life would work together on a short two stage piece of work with the aim of pulling together the key messages and testing these for relevance and resonance with the care home sector. The first stage of this work consisted of a detailed examination of the relevant reports and this brief report summarises the findings.

The PANICOA (Preventing the Abuse and Neglect in Institutional Care of Older Adults) studies aimed to

- increase knowledge of the prevalence 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 perspectives of all 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.

Five PANICOA studies were deemed particularly relevant to the care home sector. These are

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

Organizational Dynamics of Respect and Elder Care
Anne Killett, Diane Burns, Paula Hyde, Fiona Poland, Richard Gray, Andrea Kenkmann

CHOICE – Care Home Organisations Implementing Cultures for Excellence
Anne Killett, University of East Anglia, and colleagues

Four of these five studies are complete but the CHOICE study, which uses the observational tool developed in the PIECE-dem study, is not due to be completed until 2013.

The five PANICOA studies examined tended to complement each other, reinforcing and reiterating messages rather than offering contradictory evidence. Firstly we draw out common themes which have reoccurred in the studies, secondly, for each individual study, we draw out the key points from that study. **In a separate document, we will bring these together to list key issues to be taken on board by care homes.**

- The absence of abuse and neglect in the institutional care of older adults is inextricably intertwined with all other aspects of good care. It is not surprising therefore that studies seeking to find ways of minimising the chances of abuse and neglect in the institutional care of older adults, also find themselves looking at good care in a broader sense.

- The quality of residential care has undoubtedly changed for the better over the past 50 years however the likely move towards a more vulnerable and dependent care home resident population poses significant challenges for the future. In order to promote quality of life for all residents, and guard against the risk of abuse and neglect, it is important to share whatever useful evidence has emerged from the studies.

- The studies all see the need to go beyond the level of individual cases of abuse and neglect to recognise the organisational dynamics and interplay of factors that may have led to a case of mistreatment. Recognising the need to address not only abuse and neglect in care homes but also the causes of abuse and neglect.

2. Recurrent themes and messages

Several of the recurrent themes refer to the broader care home environment in which abuse and neglect may potentially occur. These themes refer to aspects of good care that minimise the chances of abuse and neglect.

- 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.

- 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.

- The care home population is changing with increasingly dependent residents, with higher levels of dementia and increased frailty, staying for a shorter period towards the end of 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.

- 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.

- Another common theme 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 be recognised, and a willingness to help with day-to-day activities, should be welcomed.

- 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 bad practice.

- 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.

- 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. The study which focussed on this issue noted that staff that deal with residents from ethnic minorities should receive training in 'cultural competence'. More than one study noted that the presence of staff recruited from overseas can itself give rise to language and communication problems.

Limitations of the studies

The studies have only taken place in care homes that agree to take part. These care homes may be atypical and the results may not provide a true overall picture. In addition, for the most part, observation has only taken place in public areas of the care home where abuse and neglect may be less common.

Products developed from the studies

The following 'products', things rather than ideas, which have been developed from the studies and which may be helpful to care home managers are ...

- The PIECE-Dem observational tool which builds on other observational tools and the Dementia Care Mapping process to provide a framework to capture the experiences of older people with dementia in the care home environment. The PIECE-Dem tool provides a useful check list of things to watch out when monitoring for the abuse and neglect of an older person with dementia.

- PEACH training materials which include a series of case studies or 'vignettes', taken from the PEACH observations, giving a basis for training through discussion rather than instruction, to draw out key issues as part of a staff training programme.

It has also been suggested that the body of information about the organisational dynamics that may lead to abuse and neglect, collected by the *Organisational Dynamics of Respect and Elder Care* study could form the basis of a future resource for care homes. Such a resource might incorporate messages from all of the studies.

3. Key themes and messages from the individual reports

3.1 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.

The PIECE-Dem study used the experience of earlier observational tools, the process of Dementia Care Mapping and the views of family carers and professionals derived from a series of focus groups and personal interviews to develop a new observational tool to highlight the perspectives and experiences of people with advanced dementia living in care homes. The tool was tested and refined in a series of three pilot studies using 7 care homes on 11 occasions but will be further tested in the PANICOA "CHOICE" study.

Key messages for care homes

- The primary output of value to care homes from "How can I tell you what's going on here?" is the PIECE-Dem observational tool which provides a framework to capture the experiences of people living with dementia in care homes.
- The elements of the observational tool also provide a useful check-list of things for family carers, staff and care home managers to watch out for when monitoring for the abuse or neglect of someone with dementia
- This study also revealed
    - the difficulty of getting care home to take part in studies of this type and a reticence to be associated with assessments of abuse and neglect.
    - the dearth of examples of good practice in the care of people living with advanced dementia in care homes.
- Many, if not all, of the indicators of risk of abuse and neglect 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, while at the same time being less able to articulate their fears and experiences.
- This study did not report detailed observational results from the pilots but previous studies have noted high levels of disengagement and inactivity for residents with dementia.

Findings from the study - the observational tool

The elements of the observational tool are summarised here because they provide a useful watch-list for relatives, care home staff and care home managers to monitor the care and understand the experiences of older people with dementia.

PIECE-Dem stands for **P**erson; **I**nteraction; **E**nvironment and **C**are **E**xperience in **Dem**entia referring to three key aspects and indicators of the care home experience of a person with dementia.

Person

Based on the premise that care should be 'person-centred' and flexibly applied to meet the needs of the individual, indicators of appropriate care include *the physical appearance of the individual*, cleanliness, tidiness, and the absence of injuries; *any overt signs of distress* including extremes of behaviour, high levels of challenging behaviour, harm to other residents and unattended distress and calls for help; *signs of agitation and anxiety* including watchfulness, wariness, tension or fearfulness particular around certain people and *withdrawn, passive or disengaged behaviou*r.

Interaction

A second key observable indicator of the risk of abuse and neglect is the nature of interactions between the resident and care home staff. Among negative indicators are *Depersonalising behaviour* including 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* including talking over the resident, no communication during an intervention, ignoring resident's requests and not attending to distress or withdrawn behaviour; *Control by staff* including verbal and non-verbal intimidation, manipulation or use of power by staff, discouraging freedom or giving orders rather than choices; *Showing overt disrespect* including the use of inappropriate terms by staff, expressing negative emotions towards the resident or labelling and objectifying residents.

Among positive indicators are *Personal identity* including individualised activities and knowledge of the resident as an individual; *Inclusiveness* including appropriate communication during interventions and interaction with staff; *Supportiveness* including equality within interactions, support in eating, supporting choice, distress and challenging behaviour skilfully handled and *Warmth* including attentiveness, patience, being focussed on well-being and showing warmth in interactions including appropriate physical contact.

Environment

A third key observable indicator is the general environment. Among negative indicators are *a general appearance of the home not being cared for* including bad smells, particularly of urine, poor decoration and a poor state of cleanliness; *Restrictions on freedom* including 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; an *Impersonal Environment* including too much noise, inappropriate TV programmes or a lack of stimulation including an absence of the resident's own personal effects including items to maintain personal hygiene.

Among positive indicators are a *Stimulating Environment* including opportunities to engage with personal object and the world in general and to take part in meaningful activity; an *Enabling Environment* including 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; a *Personalised Environment* including presence of the resident's own possessions allowing for individuality.

The PIECE-Dem overall *Care Experience* is determined by closely observing four individual residents in 15 minute blocks, with breaks in-between, over a two day period. Because of the breaks, each observer can make observations on two residents. Observation is usually restricted to observation from communal areas, which allows some observation within private space but not of personal care. Observation takes place in periods during the waking day but this could be extended to night-time observation if required. Within each 15 minute block, observation is sub-divided into twelve one minute interval with a note taken of whether the resident is involved in interaction, is engaged or disengaged. Detailed notes of the resident's activity and demeanour are taken for each minute, together with an overall note about the immediate environment. This is then summarised in a two hourly summary covering

- A perception of the observed person's predominant experience of their world, during the time period
- The extent to which the person was able to exert control
- How the person's physical needs were met
- How the person's psycho-social and spiritual needs were met
- The extent and nature of interactions
- Empathy during interactions
- The presence and use of facilities
- The emotions experienced by the observer
- An assessment of care staff experience of the person being observed
- Other comment

The observation period is preceded by a meeting with an appropriate staff member to make a final selection of the four people with dementia / high support needs to be observed, from a short-list of around eight residents for whom consent has already been obtained, and to establish a framework of knowledge about the four residents. Written consent to participate will have already been received from staff and at least one follow-up session is held with staff to provide feedback and discuss the validity of the observations.

The tool includes notes and guidance for the observer on observational practice including being unobtrusive, not observing during personal care, when and in what ways observation in bedrooms is acceptable, how to handle observer interaction with residents and what to do if harm or risk of harm, deprivation of liberty or a long period of unattended or admonished distress is observed.

The current observational tool was developed using the experience of earlier observational tools, the process of Dementia Care Mapping and the views of family carers and professionals derived from a series of focus groups and personal interviews. The theoretical underpinning of the tool came from Maslow's hierarchy of care in the 1970s[1] and the work of Professor Tom Kitwood on person centred care of older people with dementia in the 1990s. Tom Kitwood saw a person with dementia as "*a person in the fullest sense: he or she is still an agent, one who can make things happen in the world, a sentient, relational and*

[1] Maslow A H (1970), *Motivation and Personality*, New York, Harper Collins

historical being".[2] The tool was tested and refined in a series of three pilot studies using 7 homes on 11 occasions but needs further validation and it will form an important part of the "CHOICE – Care Home Organisations Implementing Cultures for Excellence" PANICOA study.

[2] Kitwood T (1993), *Person and process in dementia*, International Journal of Geriatric Psychiatry, 8 (7), 541-546

3.2 Dignity and respect in residential care: issues for black and minority ethnic groups

The primary aims of this research study were to develop understanding of the experiences of older people from black and minority ethnic (BME) communities living in care homes and their family caregivers; to explore issues of mistreatment in care homes, with a particular focus on dignity and respect; to discuss understandings of abuse, neglect and loss of dignity as BME older people, family caregivers, managers and care staff see them in the care home context; to complement work previously conducted in communities and to contribute to informing good practice in residential care for BME older people and in adult protection and to inform and complement the PANICOA programme of research.

The research study carried out interviews with 37 BME care home residents, 17 family caregivers, 10 managerial staff and 26 care staff in 6 care homes as well as carrying out 58 hours of Dementia Care Mapping observation in 4 of the care homes using DCM-8.

Key messages for care homes

The four central themes to emerge from the study findings were *relationships of care*; *culture and religion*; *mistreatment*; and *dignity and respect*.

- 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.

- 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.

- Low expectations from residents and their families may support poor care. This is particularly the case in the BME community where there may also be a lack of experience and knowledge of what to expect, in terms of good practice, from care-home care.

- Residents and family caregivers tend to view the activity of the care home day differently from staff. Each sees it from their own point of view. Residents and their families focus on themselves as individuals, their own choices actions and preferences whereas staff are task oriented, focussing on what needs to be done.

- The perspectives of staff about the care of residents, in this study, were generally more positive than those of residents and family caregivers and there a need for residents and family caregivers to feel safer in raising problems.

- Family members sometimes empathised with the difficulty of caring for their relative but felt that staffing levels were too low to cope with the demands for care. There was a reluctance to raise issues of concern.

- Cultural competence and good management were seen as important factors in preventing mistreatment which was most likely to take the form of neglect in the provision of the basic necessities of life: food, drink and the use of the toilet.

- The study highlighted the recognition of a resident's right to dignity and respect in the caring process, particularly in the area of personal care and toileting, even though the concept of dignity was not always easy to translate to all languages and cultures.

Findings from the study

The report itself listed nine 'key implications' under the four themes of '*relationships of care'*; '*culture and religion'*; '*mistreatment'* and '*dignity and respect'*. They are, in themselves, key messages for care homes and are reproduced here for ease of reference.

Relationships of care

Key implication: Managing relationships is a central element of good quality care in care homes, and can help prevent mistreatment, neglect and abuse. In multicultural contexts, racism, misunderstandings about cultural differences and problematic attitudes are additional issues that can negatively affect staff, residents and family caregiver experiences.

This confirms the relevance of relationship centred approaches to care, which are gaining increasing currency in, for example, work with family violence. Problematic relationships can promote mistreatment. Those delivering care home services need to be aware of this, and to devote resources to ensure that staff understand and can facilitate good relationships.

Prejudices about others, including racism and culturally based assumptions and attitudes can be deeply held and can damage interactions in care homes. Managers and care staff, especially if working in multicultural contexts need skills to challenge negative attitudes, which may be lifelong. Sharing the expertise that some managers and staff have across the care home sector, such as through the My Home Life network, may offer a means to tackle this complex and challenging issue.

Key implication: Good communication, beyond linguistic capacities is essential for good quality care. For BME residents, being able to use one's own language is fundamental to identity and therefore dignity, but practicalities in care homes may make this difficult to achieve.

In multicultural contexts, the availability of staff with appropriate language skills can make a big difference for BME residents and their families. Management needs to maximise the deployment of such staff. Raising the status of care work may attract more staff with appropriate linguistic skills.
In all care home contexts, good communication skills of staff are fundamental to the delivery of dignified care. Language skills alone are insufficient to promote excellent communication. In some cases, good communication may be achieved without good language skills.

These are training and workforce management issues, as well as relating to the appropriate placement of residents, in which language needs to be a consideration.

Culture and religion

Key implication: Culturally competent care in which practice is influenced by knowledge and understanding of cultural diversity can deliver general improvements in care quality.

Training in cultural competence should be part of all staff training. Cultural competence involves understanding cultural differences, but also understanding where practice needs to be modified to be appropriate to the individual.

Links with local BME communities can support culturally competent care, as local people are involved in supporting, for example, the range of preferred religious practice of residents and their families.

However, culturally competent care is not necessarily care specifically for one minority group: minorities are internally differentiated, and a policy which aimed to multiply specialised provision for every group could not achieve its objective.

Key implication: BME experiences are influenced by wider social forces, including migration and racism, as well as by cultural preferences, and these wider forces are relevant for understanding the care that residents need. BME residents and family caregivers are likely to be inhibited from complaining about poor care due to negative experiences.

Understanding of the experiences of residents is basic to ensuring the delivery of appropriate, person-centred care. BME residents may have had negative experiences related to their perceived ethnicity and may have undergone traumatic migration. Staff need to be aware that such experiences may affect attitudes and expectations of the care home.

Complaints procedures need to facilitate residents and family caregivers to feel that they can safely raise issues without fear of reprisal. A more proactive approach to participation in the care home might facilitate this.

Key implication: Low expectations from clients and their families may support poor care. They are likely to prevail in BME communities. These expectations as well as understandings of good care home practice need to be increased.

The use of care homes by BME older people is relatively new for post WW2 migrants. A proactive approach to educating communities about what they can expect from care homes could support better knowledge, and raise expectations.

Long-standing minority communities which have run care homes for generations, such as the Jewish communities, could offer lessons in how to increase awareness and raise expectations.

Key implication: The needs of and challenges faced by multicultural staff groups require recognition and support. Such staff may experience racism and other negative views from residents and family caregivers.

Staff may be on the receiving end of racism and other prejudices. Management needs to ensure that they receive appropriate support and that efforts are made to address such prejudices.

Where attitudes are deeply held, and where residents may not be aware of their comments or actions, such as with dementia, there is a need for understanding of both resident and staff issues. This is a very challenging area of practice that to our knowledge has received little discussion. It is another area in which sharing expertise across the sector could prove useful.

Mistreatment

Key implication: Prevention of mistreatment rests on recognition of residents' rights to enjoy a full life, including active participation in care relationships. A focus on basic necessities and an undemanding client group may combine to keep care at the most basic level, and fail to promote better, innovative care that can improve quality of life.

Care which is task focused and fails to address interactions, social life, spiritual life, family and community relationships has been widely criticised. It is still prevalent, and innovative care practice requires to be both supported and shared.

Improvements in care cannot be left to clients to demand, especially where they have low expectations.

Dignity and respect

Key implication: Residents are active participants in processes of good care. However, for residents to participate fully, their human rights require to be upheld, so that they can live the life they desire to lead. For BME residents, culturally competent care can support identity, autonomy and the maintenance of self esteem.

The campaign for dignity in care, which emphasises identity, autonomy and the maintenance of self-esteem, is as relevant for minority ethnic groups as it is for others. BME residents may find the expression of identity and autonomy and the maintenance of self esteem especially difficult for reasons highlighted in the report. Therefore, dignity in care work needs to pay specific attention to issues for those whose culture and experience may differ from the majority of care home residents.

A human rights approach can highlight where residential care may be failing to support residents and their families to live the lives they desire to lead.

Key implication: Dignity and respect are founded on relationships not only between staff and residents, but also between residents. Negative interactions may be more likely in multicultural environments, necessitating greater skills in care and support.

Multicultural contexts can highlight more general problems particularly sharply, for example potentially making problematic relationships more visible.

Work in multicultural contexts requires great skill, and should be appropriately recognised and rewarded.

Dementia Care Mapping

It is worth saying something about Dementia Care Mapping here because the observational part of the study used DCM-8 which differs from earlier versions of DCM and the personal enhancers and detractors of DCM-8 provide useful pointers to monitoring the well-being of someone with dementia.

The study carried out 58 hours of Dementia Care Mapping observation in 4 of the care homes using DCM-8. Dementia Care Mapping version 8 allows for the continuous

observation of a number of participants with dementia, over a representative time period in communal areas of the care facility. After each 5 minute time frame four aspects of the person with dementia's experience are recorded. The Behaviour Category Code (BCC) describes one of 24 different domains of behaviour (for example interacting with others, being passively engaged (eg watching) or being disengaged and withdrawn); secondly mood/engagement (ME) values ranging from a mood value of +5 for very happy, cheerful and absorbed to -5 for very distressed and engagement values of +5 for very absorbed to -1 for withdrawn; thirdly any Personal Detractions that may have occurred (for example intimidation, infantalisation) and lastly Personal Enhancers (for example warmth and respect). Well/Ill being (WIB) values, as used in earlier versions of DCM, can be calculated from the observed ME values.

Dementia Care Mapping categories do not, in themselves, provide information about the experiences of an older person with dementia specific to being from a black or minority ethnic group but the accompanying field notes can provide insights.

The DCM observations revealed that, in general, the four care homes observed were delivering good-quality care with the well-being of residents being good at the times and places observed.

Examples of culturally competent care were seen in the accompanying field notes, for example in the provision of food specific to the cultural preferences of the resident including Kosher food for Jewish residents and Chinese food and chopsticks for Chinese residents. Shared televisions were tuned to channels in languages that at least some residents could understand and residents were engaged in culturally specific activities and listened to culturally specific music.

Personal Detractions, as recorded in DCM, are not open to straight-forward interpretation. For example, in one home, residents were watching a religious channel and singing along, engaged and absorbed. A staff member came in and turned off the television, without offering choice, because it was time for communal exercise and singing in which they and other residents became equally absorbed.

The care homes observed using DCM were culturally mixed although one had a predominantly Jewish ethos and another was predominantly South Asian.

The Personal Enhancer and Personal Detraction types of DCM-8, used in this study, provide indicators of appropriate and inappropriate psycho-social aspects of the care of someone with dementia but not specifically those with a BME background.

DCM-8 list of Personal Detractions and Enhancers

Personal Detraction type	Personal Enhancer type
Comfort	
Intimidation	Warmth
Withholding	Holding
Outpacing	Relaxed pace
Identity	
Infantalisation	Respect
Labelling	Acceptance
Disparagement	Celebration
Attachment	
Accusation	Acknowledgement
Treachery	Genuineness
Invalidation	Validation
Occupation	
Disempowerment	Empowerment
Imposition	Facilitation
Disruption	Enabling
Objectification	Collaboration
Inclusion	
Stigmatisation	Recognition
Ignoring	Including
Banishment	Belonging
Mockery	Fun

3.3 PEACH - Promoting Excellence in All Care Homes

The PEACH study focuses on **staff** in care homes, their role and the influences upon them.

The aim of the study was to explore the needs, knowledge and practices of the care home workforce in relation to abuse, neglect and loss of dignity and to provide a preliminary evaluation of an evidence-based training package.

Following a review of earlier studies, data was gathered from a postal survey of 93 care workers, ethnographic observation in 8 care homes, interviews with 33 staff in the 8 care homes, and validated questionnaires completed by 73 staff. Focus groups were held with 29 care home managers and 15 members of the Relatives and Residents' Association. The training materials were piloted in 8 training sessions in 7 of the care homes.

Key messages for care homes

- Although earlier studies have shown that, 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.

- The postal survey, which was affected by a prolonged postal dispute and had a disappointing response rate, revealed that while the majority of homes had training on dealing with abuse less than one half had training in dealing with challenging behaviour. Of the small number of care workers who responded, the majority wanted more dementia training including how to communicate with people with dementia and manage aggression.

- The validated questionnaires revealed that, while staff had low levels of burn-out, 29% had high levels of emotional exhaustion and 41% reported a moderate or low sense of personal accomplishment. The sense of personal accomplishment was related to level of education and type of post held.

- Positive approaches to ageing and to dementia care are associated with less emotional exhaustion and depersonalisation, greater job satisfaction, a greater sense of mastery, personal accomplishment and higher levels of education.

Findings from the study

Issues raised by the observation and interviews included.

- The destabilising effect of the changing regulatory framework
- Concern at the lack of standardisation over fee structures, staff numbers, inspection, staff training and qualification and the interface with the NHS.

- The importance of first impressions and that a home should appear ‘homely’ while addressing the need for privacy.
- The difficulty in meeting the changing needs of residents as dependency increased.
- The difficulty in recruiting and retaining staff.
- Language issues for staff born overseas.
- Extensive record keeping with an emphasis on recording care rather than quality of care
- Inadequate resources
- Staff shortages
- The importance of teamwork. Teamwork may be affected by
    - Cultural tensions
    - Tensions between day and night staff
    - Tensions between staff groups – the report recorded a decision, in one home, to do away with uniforms to emphasise teamwork and bring an air of normality for residents
    - Tension between older and younger staff
- The importance of effective leadership and supervision
- 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
    - Washing and dressing
    - Moving and handling
    - Medication (including the dilemma of balancing the residents wishes not to take medication against a doctor’s prescription for improved health)
    - Managing pain
- The importance of social interaction and activities
- An observation that, on occasions, care home routines may be organised for administrative convenience rather than the benefit of residents
- Attitudes and behaviour
    - No aggression from staff towards residents was observed but staff spoke of aggression towards residents experienced in previous jobs
    - Aggression by residents towards staff was a daily occurrence, mainly associated with dementia
    - Empowering and disempowering behaviour
        - Providing choice (empowering)
        - Contradicting or patronising (disempowering)
    - Empathy and understanding
- The involvement of relatives
    - Involving relatives as volunteer support in the care home
    - Relatives as monitors of standards
    - On the negative side, the need to monitor for abuse by relatives

The PEACH study developed a training package for use in care homes, based on observed scenarios. The training package is composed of

- An initial introductory exercises explore the characteristics of ageing and older people
- An exploration of dignity and what dignified care involves – both drawn from the Educating for Dignity workbook (Tadd, 2005)
- Ten vignettes exploring the following key topics
    - Independence and Control
    - Physical wellbeing / behaviour
    - Risk and fun
    - Disrespectful practice
    - Impact of staff shortage on fundamental care
    - Dealing with relatives
    - Disrespectful communication and feeling
    - Medication and challenging behaviour
    - Team work
    - End-of-life care

3.4 Organizational Dynamics of Respect and Elder Care

This study is an examination of the organisational dynamics associated with the mistreatment (abuse, neglect and/or loss of dignity) of older people in care homes. A literature review and panel discussions (knowledge synthesis) established a basis for choosing a sample of eight contrasting care facilities for observation of practice and for interviews with residents, relatives, staff and professionals. From the observations and interviews a cross-case analysis was carried out, and the results validated by two expert panels and a stakeholder event.

The analysis focussed on the following issues

- What staff and residents do (roles behaviours subcultures)
- Organisational dynamics (relationships between staff, patients and the interaction between staff and patients as they affect care
- Perceptions of abuse, neglect and loss of dignity and high quality care

Key messages for care homes

- The problem of abuse and neglect in care homes tends 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.

- The organisational dynamics of care homes are complex and often context-specific. A particular combination of infrastructure, management, staffing, residents and other factors leading to abuse or neglect may be unique, making it difficult to draw general conclusions. The organisational balance can also change rapidly.

- Organisational factors can lead to mistreatment, preventing 'good' care by a 'good' person.

- 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, may put a resident at ease.

- Organisational factors particularly relevant to enabling or undermining responsive, person-centred care
    - Frequency and extent of organisational change
    - Low staffing levels
    - 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

- For residents the three most important issues are

- Safety and security
- Toileting
- Relationships

- Seven elements emerged as important in the organisation of care
  - Teamwork
  - Routines and work based norms
  - Openness and relatives participation
  - Meeting residents needs and skilful practice
  - Care quality and responding to mistreatment
  - Being resourceful
  - Feeling of 'being at home'

- A useful process for inspectors, managers, care staff and visiting professionals is to start with a 'known problem' experienced by residents and/or staff and identify all the organisational factors that may be contributing to the problem and how the factors interact

Findings from the study

a) Findings from the knowledge synthesis

The organisational features of mistreatment can be usefully subdivided into five facets: Organisational infrastructure; Management and procedures; Skill mix, training and members of staff; Characteristics of the resident population and Other (combined) factors.

(1) Organisational infrastructure (size; number of residents and staff; structure and physical environment; building design and architecture; general upkeep, space and provisions).

- Settings where mistreatment of older people has taken place include
  - Run-down establishments
  - Cramped conditions
  - Overcrowding of residents
  - Lack of (or unused) equipment
  - Generally poor physical environment
  - A large size home may promote regimentation and batch living
  - Poor catering and food hygiene issues
  - Unchanged bed linen
  - Strong odours of urine/faeces
  - A lack of privacy with open bathing, toileting and washing

(2) Management and procedures (organisation of the workforce; systems and practices; leadership; supervision and support of care staff)

- Key features of institutional mistreatment include
  - Poor management and/or leadership
  - Overly bureaucratic and instructive management styles

- Failure to take action following the outcome of previous investigations
- Inadequate policies and procedures including on
    - Complaints
    - Protection
    - The use of restraint
    - The management of incontinence
    - The management of medicines
    - The provision of palliative care
- Unclear lines of accountability
- Absence of supervision and monitoring of services and staff
- Absence of staff appraisal and support
- Poor judgment when recruiting new employees
- Poor work regimes including shift patterns and rigid routines and regimen.

Members of the 'provider' panel felt that operating a 'no blame culture' for mistakes that may occur means that sub-standard care is more likely to be acknowledged and rectified.

(3) Skill mix, training and members of staff

- Commonly identified staffing themes associated with mistreatment include
    - 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 including
        - 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

Panel discussions identified the quality of relationships and the organisation of staff including shift length, number on duty and consistency and continuity of the staff group as important. Residents wished to be part of the community, for example by going shopping.

Residents also wished to be involved in the day-to-day running of the home, to know the staff as individuals and have friend or family style relationships within the home.

(4) Characteristics of the resident population

- Characteristics of the resident population associated with mistreatment include
    - 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.

(5) Other (Combined) factors

- Other factors affecting the risk of mistreatment include
    - 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.

b) Findings from the analysis

- Organisational systems, how these inter-relate and how staff respond can both create adaptive systems but may also maintain fragility.

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

- The interplay between the five elements: Organisational infrastructure; Management and procedures; Skills mix, training and numbers of staff; Resident population and 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 the observed cases, particularly challenging.

- The detailed case study descriptions in the report provide an informative picture of the complexities of providing care-home care and the interaction of institution, staff and residents. The case studies include one example of how a small, person-centred change to practice can make a big difference to residents.

    - 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, puts residents at ease.

- For residents, issues of safety and security were 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.

These three themes, safety and security, toileting and relationships, provided a focus for the individual case studies undertaken.

As indicated above, the interaction of factors is complex and often context-specific, the peculiar combination of factors determining the quality of care in a particular instance making it difficult to generalise. The complexities of the organisational dynamics are illustrated by a facility where the dining room and accessible toilets are on different floors with a small lift in between. The dining room is downstairs and the accessible toilets are upstairs. Medication given out at meal time may lead to a need for the toilet following the meal. Although there are flexible meal times, in an attempt to encourage social interaction residents stay in the dining room until the end of the lunch period. This causes anxiety for residents who, when they are taken upstairs, form a toilet queue even if they do not have an immediate need for the toilet. No-one suggests installing accessible toilets downstairs, an organisational factor felt to be outside the control of care staff.

- A useful process for inspectors, managers, care staff and visiting professionals is to start with a 'known problem' experienced by residents and/or staff and identify all the organisational factors that may be contributing to the problem and how the factors interact.

Seven elements emerged as important in the organisation of care:

1. Teamwork
2. Routines and work based norms
3. Openness and relatives participation
4. Meeting residents needs and skilful practice
5. Care quality and responding to mistreatment
6. Being resourceful
7. Feeling of 'being at home'

Element in the organisation of care	**Theme emerging from interviews and analysis**
Teamwork	Human relationships, staff friendliness, relationship between carers and residents, dealing with sensitive issues; Understanding roles, structure of care, staff friendliness, ethos, diversity and community, work-based norms, leadership style
Routines and work-based norms	Work-pressures and strains, basic and intimate needs, objectification of residents by staff, structure of care, meeting general and individual needs of residents; Objectification of residents by staff, work-based norms, human relationships, choice and decision-making, structure of care, ethos, mission statement values, equity and fairness
Openness and relatives' participation	Feeling of loss and abandonment, diversity and community, roles of relatives, interface with community services, basic and intimate needs, meeting general and individual needs of residents
Meeting residents' needs and skilful practice	Basic and intimate needs, experience of decline, career of a resident, meeting general and individual needs of residents, dealing with change; Training and support, good care workers, issues of dementia, relative's evaluation of care, basic and intimate needs, human relationships, career progression of staff
Care quality and responding to mistreatment	Monitoring `and accountability, formal and informal resolutions of issues, dealing with sensitive issues, mistreatment, protecting and safeguarding, level of involvement of manager/owner, leadership style
Being resourceful	Business strategy and cost of care , equity and fairness, career progression of staff
Feeling of 'being at home'	Sense of home, communal and individual living, choice and decision-making, ethos, mission statement/values

3.5 CHOICE – Care Home Organisations Implementing Cultures for Excellence

The CHOICE study is not due for completion until 2013. Findings reported are interim, early results drawn from conversations with Anne Killett and not taken from any interim or final report.

The study aimed to highlight key practices and organisational features implicated in the positive and negative experiences of residents particularly vulnerable to mistreatment through a layered view of organisational culture: Artefacts; Values and beliefs; Norms; and Assumptions. Informant interviews and documentary analysis provided a basis for 11 case studies in care home settings using the PIECE-Dem observational framework, and an ethnographic study (semi structured interviews, observation and document collection) of the organisation.

Key messages for care homes

- Culture that supports high quality care
    - Active mediation of external pressures
    - Empowering and present leadership
    - Shared understanding of vision, purpose and practice
    - Sense of 'connectedness' within the home

Interim findings from the study

The residents' care experience relates to the culture of the home. A strong positive culture incorporates assumptions, values and norms consistent with and underpinning good care.
Key factors affecting relationships between organisational culture and care experience

- The built environment
- Connectedness within the home
- Unity of vision purpose and practice
- Empowering and distributed leadership
- Active mediation of external factors
- Human engagement and activity as part of care work
- Culture of pursuing development and engaging with change in a resident-oriented way

Connectedness may come from pre-existing membership of a social group (eg a religious faith) but this is not necessary. Person-centeredness in all practices, including recruitment and staff relationships, supports connectedness.

Unity of vision, purpose and practice within management and the staff group are important in influencing care quality. Vision and purpose needs to go beyond the organisational level and can be helped by distributed leadership. The sense of united purpose and shared values needs to go beyond senior management, with team leaders being appointed because of their knowledge of person-centred care and an ability to lead through example.

Where next

Many of the findings of the PANICOA studies reinforce what is already known about good care in care homes. The avoidance of abuse and neglect in care homes is inextricably linked with all other aspects of good care and an organisational dynamic that provides good care will also minimise the chances of abuse and neglect.

In the future, care home management and staff may find themselves increasingly under pressure from 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.

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.

It is now widely recognised that good care home care, that minimises the risk of abuse and neglect, is care that sees the resident as an individual and seeks to provide the quality of care for every resident that you would want for yourself or a close relative or friend in the same circumstances.

Centre for Policy on Ageing
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