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

Part of the PANICOA research programme

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Contents

Abstract

This aim of this research was to develop an observational framework that could be used to focus on the experience of people with significant cognitive impairment living in care homes as a means of ensuring that their perspective was included in the further study of abusive or neglectful care practice. 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 with residents in care homes, the perspective of those with significant communication problems is likely to be different and the risk is that it will continue to be under-represented unless tools are developed to capture it. A further aim of this research was to develop the observational framework in order to capture examples of excellent care that would indicate environments where abuse, neglect and loss of dignity were less likely to occur. We were mindful to develop a tool that, although would primarily be used in research, had the potential to be used by care home practitioners as a means of improving the quality of care to this group of residents.

The research took place over a sixteen month period. The first stage involved drawing together the literature and information on other observational tools that had been developed for older people and with populations such as children and people with learning difficulties who experience similar challenges in reporting abusive or neglectful practice. From this we developed semi-structured interview questions that were used in focus groups and interviews with various experts by experience.

Thirteen in-depth interviews and five focus groups were undertaken with professionals with experience of investigating allegations of abuse; care practitioners with experience of working in abusive situations in the past maybe as "whistle blowers"; family members whose loved ones have been abused; people living with dementia and family carers (who have not experienced abuse but who were interested to have their say). Researchers employed thematic analysis, and identified key themes arising from this data.

These themes were used to develop a draft observational tool, which subsequently informed the development of the observational tool to be piloted in care homes. A framework for conduct of the observation was also devised, using results from focus groups, interviews and the experience of the researchers. The observational tool was developed in practice in 7 care homes in 11 successive trials. Two researchers (four observers in all) observed in each care home. Inclusion criteria for participants to be observed included longstanding cognitive disabilities caused by a dementia disorder or stroke. Exclusion

criteria included those without significant cognitive problems, those with a history of paranoia; residents who were newly admitted or whose mental and physical health was particularly unstable. In-depth observations were conducted on 28 residents.

After each trial in a care home, the results of observation, 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. The process was finalised after 7 care home trials, repeat visits to three homes were then completed to carry out initial inter-rater reliability.

A manualised tool, the PIECE-dem Observational Process, has been built as a result of this. PIECE-dem illuminates the experience of those people who are most vulnerable in long term care settings to experiencing a poor quality of life. PIECE-dem is an acronym for:

Person
Interaction
Environment
Care **E**xperience
in Dementia

During a PIECE-dem, four residents are selected as participants to be observed in detail. As well as dementia, those selected as PIECE-dem participants have high levels of need and have characteristics which mean they are potentially most at risk of neglectful or abusive practice. Processes around the conduct of observers 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.

One researcher works with two participants during the same time period, spending time with each participant in 15 minute blocks over a two-day period, covering a typical waking day. Observations are recorded over a two day period in order to observe how different staff impact upon the experience for each participant. Using 1-minute time frames the researcher makes observations of the participants' experiences of the world around them, including recording levels of engagement, the interactions that occur with the participant and their immediate environment.

Observations occur in public areas and in hallways. Because PIECE-dem tracks an individuals' experience of care some observations are undertaken in or immediately outside the person's room. This is particularly

the case if the participant is spending long periods in bed or is bed-bound. Intimate care activities are not directly observed.

Observations are summarised every 2- 3 hours on behalf of each participant. The Summary for observation involves:

- Actions (and their possible intention) that may be observed/expressed by the **Person** with dementia, this includes their facial expression, body posture, bodily movements, attempts at communication, vocalisations;
- 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. Recording includes the posture, tone, content, apparent intent, use of touch occurring in the interaction;
- The immediate physical and psycho-social **Environment** surrounding the participant.

It had been planned that the PIECE-dem would be trialled in 15-20 occasions. Unfortunately due to low availability of care homes coming forward to take part in the trials only 11 trials were completed. Initial inter-rater reliability of the tool is good but this needs further testing. Validity testing was not possible on such a limited number of trials.

A full manual has been developed to assist research teams in using the tool in the subsequent PANICOA in-depth study of care home culture. 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.

Overview of the research process

The overall aim for this current research was to develop an observational process to capture the perspectives of people with significant cognitive impairment who are living in care homes. People with advanced dementia are more likely to be vulnerable to the risk of abuse, neglect and loss of dignity. A further aim of this research was to develop the observational framework in order to capture examples of excellent care that would indicate environments where abuse, neglect and loss of dignity were unlikely to occur. We were mindful of the opportunity to develop a tool that, although would primarily be used in research, had the potential to be used by care home practitioners as a means of improving the quality of care to this group of residents.

The starting point was founded on the teams' expertise in developing and using observation tools with people with dementia such as Dementia Care Mapping (Brooker, 2005; Brooker & Surr, 2006) and SOFI (Short Observation Framework for Inspection: Commission for Social Care Inspection, 2008). It was recognised, however, that neither of these existing tools were specifically focussed on abuse and neglect. Dementia Care Mapping provides a very rich data set about the individual experience of people with dementia in long-term care settings both in terms of levels of well-being and the quality of direct care. However, Dementia Care Mapping is a complex tool requiring an in-depth training programme to become proficient in its application. SOFI, although less complex, was designed to be part of the English inspection and regulation of care homes and has to sit within this framework in order to be used.

We were also mindful that over recent years there is a growing body of evidence that the perspective of those with mild to moderate dementia can be gained by using direct discursive methods rather than relying on observation. In developing the tool within the current study we wanted to focus on those residents that the literature had identified as being particularly hard to reach. It was decided to use the approach of building on the wealth of experience from DCM and SOFI but to attempt to develop a tool that specifically focussed on the needs of very dependent people with dementia living in long-term care situations. What were the signs that could be directly observed that people in these situations may be experiencing neglectful or abusive care? What were the signs that people were experiencing care that was supporting their well-being?

To develop such a tool required collaboration and consultation with experts on neglect and abuse in institutional care settings, combining academic and practice expertise with active involvement of older people and their carers who have experience with abuse and neglect. We were also mindful that we

wanted a tool that could be used by researchers (and practitioners in the longer term) with minimal training. We also recognised that such a tool could be very powerful in helping staff and professionals providing care gain insight into the challenges faced by their most vulnerable residents and assist in improving the quality of care for this group.

Thus, this study aimed to develop a robust and sensitive tool that could be used both by researchers and practitioners to assess the prevalence and experience of abuse and neglect for those with very limited or fluctuating cognitive abilities. The aim was to develop a tool that focussed specifically on observable signs of abuse and neglect or risk factors associated with this. It was also recognised that there are positive features in care home environments that make abuse less likely to occur. For this reason the aim was to build into the tool to capture examples of excellent care that would indicate environments where abuse, neglect and loss of dignity are unlikely to occur.

This study was funded by the Department of Health PRP and Comic Relief as part of their PANICOA (Preventing Abuse and Neglect in Institutional Care of Older Adults) research initiative (www.panicoa.org.uk) that commissioned a number of separate, but linked, studies to examine the issues around abuse, neglect and loss of dignity from a range of different perspectives and by a variety of means. At the outset it was proposed that the observational tool developed as part of this research would be used in a national prevalence study of abuse of older people living in care homes. During the time period that this research was undertaken, a decision was taken that a national prevalence survey in care homes, as initially envisaged, would be replaced by a more in-depth qualitative enquiry into the culture of care in care homes. The intention is that PIECE-dem will be used in the final PANICOA study as setting the focus for in-depth qualitative ethnographic observation and interviews examining organisational culture in relation to good care/mistreatment.

Structure of this report

Part 1: *The Context of the Study.* This section covers the background and literature that informed the subsequent research.

Part 2: Gathering the Views of Expert Stakeholders. This section covers the time period January to April 2010. It sets out the methods and results specific to the stakeholder meetings, focus groups and interviews. It concludes with the pilot version of the tool to be trialled in the care homes.

Part 3: The Care Home Pilots. This section covers the time period May – November 2010. It sets out the methods and results specific to the development of the tool in a series of care homes study sites. This

permitted in vivo modifications to the pilot tool and resolved practical data collection problems. At the end of this stage we had developed PIECE-dem. The final tool was fully operationalised and a full instruction manual was prepared. ***The PIECE-dem manual forms Appendix 1 of this report***.

Part 4: Discussion and next steps. This section sets the knowledge in context, details some of the limitations of the current study and details next steps.

Ethical approval

The research project was submitted to through NRES to the North Staffordshire Research Ethics Committee which was an NRES committee with expertise in reviewing research proposals dealing with adults without capacity to consent. It was provided with a favourable review in October 2009 (REC reference number 09/H1204/79).

The ethical approval covered both stages of the research including the gathering of the views of the expert stakeholders and the care home pilots. The specific ethical issues and consent procedures are covered in Parts 2 & 3 of this report.

Steering Group

The steering group consisted of seven individuals who were sophisticated in their understanding of the issues to do with neglect and abuse as it impacts on people with dementia in care homes. They were independent of the research process but offered valuable advice on the development of the tool and its implementation. They also helped the research team consider the ethical issues involved in undertaking observations in care homes – for example we had an in-depth discussion about whether observations should take place in bed-room areas. The steering group consisted of two academics with research experience in abuse relating to older people and learning disabilities, a safe-guarding lead who had been involved in the development of SOFI, two family carers whose mothers had dementia and who had experienced poor care, a nurse consultant in older people's mental health, the dementia lead for a large for-profit care home chain who had been successful in improving care standards and a member of the safe-guarding vulnerable groups team at the DH. The steering group were due to meet three times over the project. Unfortunately, due to heavy snow in January the first meeting was cancelled but all members provided individual telephone advice about the conduct of the interviews and focus groups with the research team at this point. The second meeting was during the development of the pilot tool and the third meeting was at the end of the care home pilots.

Patient and Public Involvement

The objective of this research was to shine a light on the experience of a group of people who are often excluded from research programmes – people with advanced stage dementia. The whole aim of this research was to ensure the experience of this group was taken into account so PPI was at the heart of what we were trying to achieve.

We consulted with people with dementia on our organisations' steering groups about whether to undertake this research and it was seen by them as being of a very high priority. We also sought out people from the Alzheimer's Society as participants. As part of the first stage of the research we held an in-depth focus group members of Birmingham branch of the Alzheimer's Society who were all people living with a dementia diagnosis but not resident in a care home. They again thought that this was an important area of research and underlined the importance of people not losing their identity and relationships and dignity if they needed to go into a care home.

Family carers of people with dementia living in care homes were also actively involved in the research process. They took part in focus groups and interviews to help us build the tool. Four family carers with experience of their loved one experiencing poor quality care in care homes were interviewed face to face and another four took part in a focus group. The steering group for the research included one current family carer with a mother living in care home and another family carer with past experience of this. These steering group members were important in underlining the importance of the research and of underlining how vulnerable this group is to poor quality care.

The topic of this research with its focus on abusive and neglectful practice was very emotive and challenging for people with a dementia diagnosis and family members. We took the setting up and facilitation of interviews and focus groups very seriously. People living with dementia offered some very powerful insights into what they would look for in a care home. The focus groups were audio recorded and detailed notes were made during the group itself. Participants provided formal consent for the audio recording prior to the meeting commencing. Some were held at the university, others in local Alzheimer's Society venues. Care was taken to create a supportive and relaxed environment where people felt comfortable to contribute.

At the commencement of the focus group meeting there was the opportunity for introductions, explaining the nature of the groups and answering any questions. Given the nature of the discussions we recognised that there was a risk that participants may have found some of the discussions upsetting or distressing. The

member of the research team who led the interviews and the focus groups was an experienced Admiral Nurse and a Nurse Consultant in mental health services to older people. She utilised her clinical as well as her research skills within this role. Support for participants was made available after the focus group was completed if needed. Focus groups were scheduled to last for around 90 minutes. Focus group participants were asked to ensure that where possible anonymity of persons and organisations was maintained when discussing personal experiences.

For family members who were currently caring for relatives who were in care homes where care was not good, we decided to interview people in a one to one situation. Although this took more time it meant that when painful emotional issues were discussed that these could be dealt with sensitively and fully. This stage of the research took more time than we had anticipated but the richness of the material we gained from our interviews and focus groups meant that the outcome of the research was grounded in these experiences.

Part 1: Context of study

The challenge of dementia

Dementia is the biggest health and social challenge facing the developed world. Five percent of people over 65 and 20% of those over 80 have dementia, with 750,000 in the UK alone, a number that will continue to rise as the age of the population rises with enormous implications for care provision (Knapp et al. 1998). With this growing ageing population globally the need for ways of providing care for people with dementia that is humane and person centred is a key concern for politicians, commissioners and care providers.

Approximately 250,000 people with dementia live in care homes (Alzheimer's Society (2007) representing approximately 37% people with dementia living in the UK, costing in excess of £9 billion per year in social care (Alzheimer's Research Trust, 2010). This group of people have the most complex needs and the highest levels of dependency of all those with dementia, often having multiple physical, cognitive and functional mental health difficulties (Fossey & James, 2008). Behavioural and Psychiatric Symptoms of Dementia such as aggression, agitation, depression and psychosis (Margallo-Lana et al, 2001) are widespread and these difficulties are exacerbated by the inappropriate long-term use of antipsychotic drugs (All Party Parliamentary Group, 2008). One of the key goals of the National Dementia Strategy (DH, 2009) was to improve the quality of care for people with dementia in care homes. A review of antipsychotic prescribing (Banerjee, 2009) recommended a substantial reduction in unnecessary prescribing. This adds further weight to the recommendations of the NICE dementia guidelines (NICE/SCIE, 2007) to improve the treatment and care for people with dementia in care homes.

Dignity in care is high on the government agenda across health and social care. The *No Secrets* (Department of Health 2000) guidance brought about major changes to adult protection in its provision of a framework for responding to abuse of vulnerable adults. In 2006 the Dignity Campaign was launched which aims to create a care system where there is no tolerance of abuse. At a local level dignity is promoted through National Performance Indicators in the NHS and abuse and dignity feature more prominently in the regulatory inspections carried out within health and social care. However, while current strategies, initiatives and guidance all seek to improve care practices with regard to dignity and abuse and systems for protecting those who are most vulnerable, none have identified or sought to identify the prevalence of abuse, neglect and loss of dignity. Thus, the extent of the problems being tackled remains relatively unknown. The House of Commons Select Committee on Elder Abuse (House of

Commons Health Committee 2004) recommended that the extent of the problem should be accurately determined and that performance indicators should be developed to enable accurate measurement and inspection of establishments providing care to vulnerable adults in particular those which increase user engagement.

Person-centred dementia care

Over the past thirty years there has been a sea-change in how we view the lives of people with dementia. In 1986 in the UK the Kings Fund published "Living Well into Old Age" which provided an explicit statement that people with dementia had the same rights and value as anyone else in society. The fact that an explicit statement had to be made at all is indicative that it was not a view universally held. From a philosophical standpoint, historically, the definition of person was seen as being dependent on consciousness of thought (being able to think about yourself thinking) and continuity of memory (being able to know your continuous life story). Using this definition would mean that an individual with dementia would not be seen as the same "person" as their dementia progressed because their continuous memory of themselves would change. At the most disabling stages of dementia, when consciousness of thinking is no longer evident, "the person" would cease to exist. Using this definition, as dementia destroys the brain it also destroys the person. This fits well with the view of dementia as a living death that just leaves the body behind. If we view someone as "dead" then their quality of life is of little importance.

This view had been vigorously challenged (Hughes, 2001) in defining a person as a "situated-embodied-agent" rather than relying on consciousness of thought for the definition. Defining the concept of person in this way means that we should aspire to treat people with dementia at all stages of their disability, in the way in which all people would wish to be treated. Similarly, Kitwood (1993a) described the 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 historical being"* (p541)

It was the late Professor Tom Kitwood who first used the term person-centred in relation to people with dementia. Writing in the year before his death, Kitwood (1997a) said that he used the term 'person-centred' in the context of dementia care to bring together ideas and ways of working with the lived experience of people with dementia that emphasised communication and relationships. The term was intended to be a direct reference to Rogerian psychotherapy with its emphasis on authentic contact and communication.

Kitwood's work was part of the ground swell of psychosocial approaches to dementia care that came into being during the 1980's and 1990's. Reality Orientation (Holden and Woods, 1988) was, in part, a response to offer reassurance to the person with dementia and a means of decreasing disorientation. Validation therapy (Feil,1993) and Resolution therapy (Stokes & Goudie 1990) emphasised the importance of using the experience of the person with dementia as the starting point. Work on individualised care planning and social role valorisation, with its roots in the Learning Disabilities field, quickly caught on with those working in services for older people who were concerned to understand the people they cared for at a deeper level and to provide them with opportunities for leading a valued life.

The disability rights movement and the growing dissatisfaction with institutionalised care led to various codes of practice from the Kings Fund in the UK during the 1980's that emphasised the rights of people with dementia to live well. The work of Steven Sabat (Sabat, 1994) was influential in shaping thinking about the impact of social environments on people with dementia. As far back as 1985, Joanne Rader and colleagues (Rader, 1985) used the term 'agenda behaviour' to highlight the goal-seeking driving much of the behaviour of people with dementia. The "Pioneer Movement" in the USA has been working on changing the culture of nursing home care for many years (Lustbader, 2000). The ideas of Bill Thomas and the Eden Alternative (Thomas, 1996) give the experience of the person with dementia a centrality that was absent from approaches that had seen dementia care as a set of problems to be managed.

Writing throughout this period, Tom Kitwood published a continuous stream of articles in prominent journals during the 1980's and 90's (Kitwood, 1987a; 1987b; 1988; 1989; 1990a; 1990b; 1992; 1993a; 1993b; 1993c; 1995a and 1995b). He brought these ideas together in his most well-known book *Dementia reconsidered: The person comes first* (1997a). He focussed on the maintenance of personhood as being central to person-centred care. He defined personhood as:

> *"a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust"* (Kitwood, 1997a p8)

The primary outcome of person-centred care for people with dementia is to maintain their personhood in the face of declining mental powers. There is an assumption in person-centred care that people with dementia have the capacity to experience relative well-being and ill-being. A simplistic biological model would interpret the expression of ill-being as a random occurrence or as a sign of brain pathology. In person-centred care the assumption is made that behaviour has meaning. According to Kitwood, high levels of challenging behaviour, distress or apathy occur more commonly in care settings that are not

supportive of personhood. In care environments that are supportive of personhood, we expect to see a greater preponderance of well-being and social confidence.

Kitwood's view of person-centred care for people with dementia was that it took place in the context of relationships. He wrote a great deal about this and the way in which the social psychology could be supportive or damaging to people with dementia. As verbal abilities are lost, the importance of warm, accepting human contact through non-verbal channels become even more important than before.

With the onset of dementia, individuals are very vulnerable to their psychological defences being radically attacked and broken down. As the sense of self breaks down, it becomes increasingly important that the sense of self is held within the relationships that the person with dementia experiences. These relationships cannot be developed through the traditional therapy hour as in person-centred psychotherapy. Rather the development of relationship occurs through the day-to-day interactions.

In communication and interactions, personhood is undermined when individual needs and rights are not considered, when powerful negative emotions are ignored or invalidated and when increasing isolation from human relationships occurs. Kitwood described the various common ways that he had observed personhood being undermined in care settings, coining the phrase 'Malignant Social Psychology' (MSP) as an umbrella term. MSP includes episodes where people are intimidated, outpaced, not responded to, infantilised, labelled, disparaged, blamed, manipulated, invalidated, disempowered, overpowered, disrupted, objectified, stigmatised, ignored, banished and mocked.

Very few people would wish to deliberately subject other people to MSP. Kitwood was at pains to say that episodes of MSP are very rarely done with any malicious intent. Rather, episodes of MSP become interwoven into the care culture. This way of responding to people with dementia gets learnt in the same way that new staff learn how to fold sheets. If you are a new staff member in a nursing home, you learn how to communicate with people with dementia from other staff with whom you work. If their communication style with residents is one that is characterised by of infantilisation and outpacing then you will follow their lead. The malignancy in MSP is that it eats away at personhood of those being cared for and also it spreads from one member of staff to another very quickly.

Kitwood also described what a positive social psychology might look like for people with dementia. If personhood is undermined by MSP then it should also be possible to describe the sorts of everyday interactions that would promote the maintenance of personhood. He used the term 'Positive Person Work' to describe ten different forms of interaction that would maintain personhood. These were labelled

recognition, negotiation, collaboration, play, timalation (engagement through the senses), celebration, relaxation, validation, holding and facilitation (Kitwood, 1997a p90-93)

The writings of Tom Kitwood have been enormously influential in the dementia care. The term 'Person-Centred Care' has become all-pervasive. As with many terms that are frequently used there is a danger that it loses links with its original meaning.

For example, although the National Service Framework for Older People (DH, 2004) made mention of person-centred care as a standard to aspire to, it defined person-centred care simply as treating people as individuals and providing them with packages of care that meet their individual needs. The emphasis here does not encompass relationships or the culture of care or the maintenance of personhood. Although person-centred care emphasises seeing the person as an individual, if it is just defined in this way then the focus is only on those individual needs that are covered by being a patient or a resident.

There is a danger that by just focussing on individualised care that the person with dementia stays firmly hidden behind their disease label and that person-centred care still does not occur. Although it is not possible to do person-centred care without taking an individualised approach, it is possible to do individualised care that is not person-centred. By inserting a problem focus into individualised care can make it difficult to continue to see the person as an individual in the round.

The VIPS definition of person-centred dementia care (Brooker, 2004; Brooker, 2007) was an attempt to redress this misconception. Person-centred care as it relates to people with dementia has become a composite term and any definition needs to take this into consideration.

Put simply, the VIPS definition of person-centred care encompasses:

V   A value base that asserts the absolute value of all human lives

I   An individualised approach, recognising uniqueness

P   Understanding the world from the perspective of the person living with dementia

S   Promotion of a positive social psychology in which the person living with dementia can experience relative well-being

The VIPS definition was used in the National Institute for Health and Clinical Excellence (NICE) /Social Care Institute for Excellence (SCIE) Guideline on Dementia (NICE, 2006), which defined the principles of person-centred care as asserting:

- The human value of people with dementia, regardless of age or cognitive impairment, and those who care for them;

- The individuality of people with dementia, with their unique personality and life experiences among the influences on their response to the dementia;

- The importance of the perspective of the person with dementia;

- The importance of relationships and interactions with others to the person with dementia, and their potential for promoting well-being.

Person-centred care and the ideas that influence it continue to grow. In many respects, these ideas no longer seem radical. The challenge now is how we get these principles into everyday practice.

Care home environments

There is a particular challenge of how we assess the impact of person-centred care culture in care homes for people living with advanced dementia. People with advanced dementia face enormous challenges with having their personhood needs met. Arguably, they are the people who most need regular nurturing contact from their care givers, but they are those who are least likely to receive this.

The history of study of care in institutions is rich and the sequestration of people with dementia is central to contemporary Western culture where institutions comprise residents and staff who are separated by power, social distance and access to information. Historically, at least from the Classical Age to the twentieth century, the aged and the insane have been dehumanised and frequently confined to institutions (Goffman 1961; de Beauvoir 1970; Szasz 1975). Goffman (1961) explored in depth the impact of institutional care and how it transforms people's identity and self-esteem through the 'mortification of self', removing most vestiges of a former life to produce a new identity. Treatments are often used to reinforce these rituals of dispossession and individual, everyday activities often require permission from those in authority (Goffman 1961). This system is maintained subtly under the rationale of the person's best interests. Goffman pointed to the ways in which identities were (re)made through the 'institutional arrangements' of the institution, whose unique and insular world legitimated certain patterns of interaction:

> *"The self, then, can be seen as something that resides in the arrangements prevailing in a social system for its members. The self in this sense is not a property of the person to whom it is attributed, but dwells rather in the pattern of social control that is exerted in connexion with the person by himself and those around him. This special kind of institutional arrangement does not so much support the self as constitute it"* (Goffman, 1961: 154)

Dementia renders people vulnerable and dependent upon others for the provision of their care needs and leads to suggestions that they are no longer persons. Mitteness and Barker (1995) and Oliver (1999) suggest that the symptoms that occur in the person with dementia, such as incontinence, unstable mobility and babbling speech symbolise a loss of control that is culturally 'incompatible with adulthood' (Mitteness and Barker 1995:191). This sequestration and social rejection has also been identified in institutions for people with severe physical disabilities in long-term care (Miller and Gwynne 1972; Dartington *et al* 1981). People with dementia are often referred to within the same context as those who are dying, without acknowledgement of the terminal state of the disease, and in some cases referred to as 'already dead' (Gubrium 1986; Orona 1990; Herskovits 1995) while they are quite obviously physically alive.

Oliver (1999) analysed attempts by an institution to impose structure and control on the daily lives of residents with Alzheimer's disease, in a residential setting and developed a concept of 'ordering the disorderly'. The study revealed five 'imposition of structural controls' over the lives of the residents. These were: temporally, physically, materially, organisational, and behaviourally and linguistically. Temporally refers to a strict regime of time structure which tended to create a sense of depersonalisation of residents. This related to the daily activities of people with dementia. Control and concealment was also *physically* imposed. This was the manner in which the unit was placed, i.e. beside a medical centre, 'medical gaze' and surrounded by residential areas, 'normality'. An illusion of order is presented behind which were 'decorated' locked doors. Materially, the setting and décor of the units are designed to promote an 'image of tranquillity' and Oliver (1999) suggests that these serve to conceal the disorder, the bodily degeneration and decay contained within the units. Organisational and bureaucratic measures were used to take away any time that could be spent with the residents on a personal level (Oliver 1999). Behaviourally and linguistically residents were categorised and stereotyped according to their behaviours and the denial of personhood was perpetuated through infantilisation and humiliation (Oliver 1999). Others have also conceptualised care using the infantilisation thesis (Hockey and James 1993), suggesting that lack of or loss of attributes of physical, cognitive and emotional maturity means individuals can be regarded as 'unpersons'. When certain groups of older people are regarded in this way, they are transformed into metaphoric children (Hockey and James 1993) with the nurses who care for them acting as their metaphoric parents.

Intertwined and in parallel to the sea-change in how the lives of people with dementia are construed there has also been a shift towards more positive constructions on how we view care home cultures. Tobin's (1999) work about the preservation of the self highlighted the importance of the psychosocial aspects of

the care environment. According to Tobin, it is the warmth of staff in relationships, the availability of personally meaningful activities and stimulation, the tolerance for resident deviance and the extent to which residents are perceived and treated as individuals that define quality of psychosocial care.

Sabat's (2001) demonstration of social positioning with respect to people with dementia lends empirical support to the manner in which interactions enhance or diminish a person's sense of self. His work also provides evidence of the way people with dementia actively cope with how they are treated. The centrality of the relationships between care staff, residents and families as maintaining well-being of all these groups was brought together in the model of 'relationship centred care'. Through a series of interviews and observational studies Mike Nolan and others (Nolan et al, 2001, 2008) provided the Senses Framework demonstrating that quality of care is dependent on the relationships between the older people, care staff, and family carers. Good quality in the relationships was conceptualised by achieving a sense of security, continuity, belonging, purpose, achievement and significance for each party. The Senses Framework and relationship centred care was the conceptual framework for the "My Home Life" (Help the Aged, 2006) Programme. Following on from the publication of this report **My** Home Life http://myhomelifemovement.org was setup as a collaborative programme aimed at improving the quality of life of those who are living, dying, visiting and working in care homes for older people by sharing best practice and enhancing quality of care.

This approach addresses the larger organisational context of care provision. The practice of caring for very vulnerable people in large groups with low staffing levels can place care workers in an intolerable bind when trying to provide person-centred care. If care homes are to deliver person centred care in anything but a non-trivial manner, the rights of all people regardless of age and cognitive ability has to be driven from the top down. The person-centred approach is about the building of authentic relationships. Organisations that adopt a person-centred approach to care also recognise the need to work by the same set of principles with their staff. If the personhood of an individual member of staff is not respected then she in turn will find it difficult to maintain respect for those she cares for over a sustained period of time. Direct care workers for older people are one of the lowest paid groups in health and social care, often working in poor conditions with high risk of injury (Noelker and Ejaz, 2005). Providing care in a humanistic and person-centred way is a challenge where front-line care-staff often feel under-valued (Skills for Care, 2007). Consequences for staff can be demoralisation, burnout and stress, lower work satisfaction or job clarity, lower psychological well-being and high workforce turnover (Moniz-Cook et al, 1997; Cole et al, 2000). Staff burnout has been shown to be associated with less willingness to help residents, low optimism and negative emotional responses to their behaviour (Todd and Watts, 2005). High levels staff turnover, staff shortages and poorly trained staff exacerbated feelings of depression in care home residents (Choi et al, 2008). Empowering

direct care staff through adequate induction and training is a crucial first step towards improving the lived experience of care for people with dementia.

Likewise, building relationships with families of residents are important in the life of any care home. Actively encouraging families to maintain relationships with their loved ones can make a positive impact on the lives of residents and staff (Woods et al, 2007). Without active encouragement family members or people with dementia can often feel marginalised, confused and excluded (Hennings et al, 2010). Care home providers need to put processes in place that actively welcome families into the life of the care home. Family carers often struggle with their own overwhelming feelings when the person they care for moves into a home. Where care homes do not understand and accept these feelings and carers are not made to feel welcome, they may be increasingly reluctant to visit. This can deny residents an important link with the past and their core identity.

Including the perspective of the person with advanced dementia

For people with advanced dementia living in care homes, their quality of life is inextricably linked with quality of care. As dementia progresses the ability of individuals to secure help in their own right or to assert their best interests in the face of poor service quality, becomes increasingly difficult. Unless the person with dementia is blessed with a strong family support structure they may have very few advocates who will act solely in their best interests. Because of this, their citizenship rights are easily violated. This renders them extremely vulnerable to abuse – be it financial, physical, sexual or psychological. Individuals living with dementia are likely to find it difficult to complain directly about poor quality of care because of the nature of cognitive disability that is part and parcel of dementia. In addition, many family members are worried that if they complain services will be taken away from them or that there will be repercussions for their loved ones.

Gaining the perspective of people living with dementia in care homes is a challenge but over recent years it has become widely accepted that this challenge needs to be met if we are to conduct research and development from a value base of including the views of all stakeholders. There are three major processes available in research to gain access to the perspective of a person with dementia – interviews including use of structured questionnaires; proxy reports; and observation (Brooker, 2008).

Many accounts of living with dementia have come directly from interviews and focus groups with people who have dementia, speaking about their own experience. Useful guidance about how best to interview people living with dementia, to elicit their views and take some of the barriers into account are now

available (McKillop & Wilkinson, 2004: Murphy, 2007 Bamford & Bruce,2002). The guidance emphasises the idea of partnership, the importance of building a relationship and rapport between the interviewer and the person with dementia, being proactive in maximising the likelihood of good communications and in attending carefully in interpreting what is being communicated. Often, audio-taping and transcription can bring to light insights of this nature that may have been missed on first hearing.

There is now a wealth of evidence to support the idea that people with dementia can express preferences (Feinberg & Whitlatch, 2001). The development of "Talking Mats" as a means of helping people with early and moderate stage dementia in making decisions about managing their daily lives has been a particularly helpful development in this area (Murphy et al, 2010; Oliver et al, 2011). Talking Mats is a low- technology communication framework, developed at the University of Stirling, to help people with communication difficulties express their views. It uses a simple system of picture symbols, placed on a textured mat, allows people to indicate their views about various options within a topic by placing the relevant image below a visual scale. Although primarily used with people with mild to moderate dementia in has been shown to have efficacy within care home settings (Macer, 2011). Over recent years there has been a plethora of dementia specific quality of life questionnaires published. Many of these involve the person with the dementia completing the questionnaire as part of a structured interview with a researcher. Scholzel-Dobenbos et al (2007) reviewed nine instruments for rating quality of life for people with dementia, three of which were dementia specific. Evidence is provided that these can be used reliably with people with mild to moderate dementia.

There is a significant subset of people living with dementia particularly in long term care settings, however, who find it very difficult to express themselves verbally. In some respects, this would not be so much of a problem if the experience of those who could speak out was similar to those who cannot. For example, in care homes where some of the residents who can take part in interviews are reporting high levels of satisfaction then it might be reasonable to assume that people with advanced dementia were also happy. There is evidence to suggest, however, that residents who are able to participate in interviews may have very different experiences of care than people with advanced dementia (Thompson & Kingston, 2004). Within a care-home setting for example, those residents who are more socially able are likely to have more staff and visitor contact. The person who finds it difficult to achieve eye-contact and who has very limited capacity for speech is likely to attract less attention.

When people have difficulty speaking for themselves about their situation it is common practice to ask someone who knows them well to speak on their behalf. In the case of people living with dementia this is often the person's next of kin or, failing this, a health or social care worker who has knowledge of their current situation. This is generally known as a proxy opinion. Some of the structured quality of life instruments have versions of the same instrument that can be completed both by the person with dementia and their proxy – either family member or key-worker. Whilst proxies may be able to provide answers that would concur with the person with dementia on some occasions, there are others where they would not. Family carers often have significantly different views of quality of care and quality of life to people with dementia (Aggarwal et al, 2003). There is also a fairly consistent finding that residents in nursing homes rate their quality of life as better on a variety of dimensions than staff do when asked to rate quality of life as a proxy on behalf of residents. Mittal et al (2007) systematically investigated factors that widened the gap between resident rated and staff proxy rated quality of life. Interestingly, a key finding was that higher job satisfaction on the part of the staff meant that they were more sensitive in rating their residents' quality of life as they would themselves.

Observational methods have been used for many years in assessing dementia care. Observation can either be structured or unstructured, systematic or casual. In a research context observation forms the basis of scientific method. Participant observation is a well used method in qualitative research. Structured observational methods developed specifically for evidencing quality in long-term care settings have been around for many years (e.g. Godlove et al, 1982). Many of the observational methods in dementia pre-date the now widely accepted evidence that people with dementia can and should be encouraged to speak out on their own behalf.

An early review of observational methods looking at aspects of quality of life in dementia (Brooker, 1995) identified five different structured methods including patient engagement (McFayden, 1984); the Short Observation Method (SOM) (MacDonald et al, 1985); the Patient Behaviour Observation Instrument (PBOI) (Bowie & Mountain, 1993); the Quality of Interactions Schedule (QUIS) (Dean et al, 1993) and Dementia Care Mapping (DCM) (Kitwood & Bredin, 1992). Later observational methods in the dementia care field include the DS-DAT (Volicer, 1999) which is a direct observation scale to assess direct signs of comfort-discomfort in people with severe dementia. The Affect Rating Scale (Lawton et al, 2001) has been utilised widely in the US. These observational methods all offer a structured way of trying to observe the experience of people with dementia living in formal care settings or using services. They are used generally in communal care settings where the observer can "fade" into the background and observe a number of

people at the same time. Most include complex codings of behaviour and require a period of training to become proficient. Video and digital recording have also been used in care settings and with individuals. These recordings provide the advantage of being able to replay and provide very fine-grained analysis (Cook, 2002).This enables in-depth observation to occur without the imposition of pre-determined categories. Video evidence can be particularly valuable when working with people with very advanced dementia whose speech on first listening seems meaningless – but on repeated replay shows clear attempts at communication (e.g. Killick & Allan, 2006)

Although these methods would not be appropriate to use in situations where people with dementia could speak out for themselves they do enable the experience of people with more advanced dementia and complex needs to be included. The focus of the current study on people with more advanced dementia and complex needs draws on these previous observational studies and tools. The work of the first author with DCM (Brooker, 2005) was a starting point for developing the PIECE-dem. Observational methods provide the opportunity to provide the perspective of those who experience significant challenges in speaking out for themselves. They provide evidence of what happens to people with dementia in communal areas of formal care settings. They provide evidence of how people spend their time, their observed well-being and how they are treated by staff and professionals. There is a concern that observations may in themselves diminish the quality of life of people with dementia by making them feel intimidated. With our existing work in up-dating DCM (Brooker and Surr,2005) we have developed a number of processes to ensure that service users and staff do not feel marginalised or intimidated by the observation process. We planned to utilise this experience in the development of PIECE-dem. We decided to use direct observation rather than video recording because of the additional ethical and practical challenges that video-recording would bring.

The research team also drew on their experience of the development of The Short Observation Framework for Inspection (SOFI) as a method for observing the care of people with dementia when inspecting the standards of care in English care homes (Brooker et al, 2007). SOFI was developed in collaboration with the former Commission for Social Care Inspection (CSCI) who have been superseded by the Care Quality Commission (CQC). This body has responsibility for monitoring standards in residential and nursing homes. SOFI involves structured observation of a sample of five residents in a communal area, often over a lunch time period, usually for a period of a couple of hours. Although the observation time is relatively brief, inspectors have the advantage of doing this as part of an in-depth evaluation in which they can interrogate other records in a care home, interview staff and residents and seek to triangulate evidence and explore themes through case tracking. SOFI was not designed as a stand-alone measure. It is always used in

conjunction with other inspection tools such as interviewing service users, staff, significant others and a review of records. Through using SOFI, the inspector attempts to tune into the residents' experience, something that is often not possible through interviewing people over such a short time period. It can be thought of as providing information which forms part of a jigsaw or picture about what the residents' experience. Such a picture can enable inspectors to drill down to practice issues such as care culture, staff training and over use of medication. SOFI was subsequently utilised in a thematic inspection of the care or people with dementia in 100 care homes (CSCI, 2008). The development of a new observational tool for a specific purpose around regulation and inspection and its subsequent use across a wide range of care homes, gave us confidence that we would be able to develop an observational tool for the purposes of the current study.

Within this context of providing the perspective of people with advanced dementia we drew on the best practice from existing observational tools, recognising that the observations could be triangulated with evidence gained from other sources such as interviews, focus groups and documentation to provide a comprehensive picture of the likelihood of abuse, neglect and loss of dignity occurring in care home settings.

The risks of abuse and neglect for people living with dementia

Abuse has been defined as, "… a violation of an individual's human or civil rights by any other person or persons *(Department of Health 2000 p9)"* It may be single or repeated acts which are physical, sexual, psychological, financial or material, neglect or acts of omission or discrimination. Abuse can result from deliberate intent, negligence or ignorance. An in-depth examination of definitions and descriptions of mistreatment in care homes have emphasised the centrality of the expectation of trust and a duty of care towards someone in a relative position of less power (Dixon et al 2010). It is estimated that around two-thirds of people living in care homes have some degree of dementia (Knapp, Prince et al. 2007). People with dementia are particularly vulnerable to poor care and continual monitoring of their care is required (Goergen 2004, Benbow 2008). In terms of relative poser within institutional settings, those with advanced dementia are arguably the least powerful and the most vulnerable to mistreatment.

Studies examining mistreatment in care homes have relied wholly on carer report, often excluding the perspective of those most vulnerable to abuse. A systematic review of the limited number of studies examining the prevalence of abuse of older people living in care homes (Cooper, Selwood et al. 2008) reports prevalence rates of 16%-40% of care staff reporting they have committed serious psychological abuse, 10% physical abuse and 79-99% admitting having observed the occurrence of abuse. Therefore, it is clear that abuse and neglect of older people in care comes is occurring with some regularity. In all studies

rates of abuse and neglect of older people appear to be highest in the most dependent older people (Dyer, Pavlik et al. 2000; Asti and Erdem 2006), For example, Selwood and Cooper (2009) report prevalence rates in the general older population of around 6% of people experiencing abuse in the last month which rises to around 25% in vulnerable populations such as people with dementia . Therefore, people who have dementia resident within care home environments would appear to be those who are at the greatest risk of being subject to abuse or neglect. However, there is very little published research that specifically examines prevalence rates or types of abuse and neglect experienced specifically by people living with dementia in care home settings.

This lack of evidence about abuse and neglect of people with dementia relates to a number of factors, which are usually methodological or ethical in nature. For example, many of the studies specifically excluded people with dementia from their sample due to difficulties in gaining informed consent or people with dementia being unable to complete the interviews or questionnaires by which data on abuse and neglect is captured. Where abuse of people with dementia was the primary focus of the research, studies have almost entirely recruited people with dementia and family carers living in the community and have used qualitative interviews to obtain prevalence data (see for example Coyne, Reichmen et al. 1993; Sadler, Kurrle et al. 1995; Buckwalter, Campbell et al. 1996; Compton, Flanagan et al. 1997; Dyer, Pavlik et al. 2000; Hansberry, Chen et al. 2005; Asti and Erdem 2006; Cooney, Howard et al. 2006; Matsuda 2007; Wiglesworth, Mosqueda et al. 2010).

Not all persons with dementia are able to participate reliably in qualitative interviews. Thus, the perspective of people with greater dependency levels, who are most vulnerable to abuse, is excluded from the research literature. Studies examining abuse and neglect in care homes have relied wholly on carer report, again excluding the perspective of those most vulnerable to abuse. While high levels of abuse have been reported in surveys of professional caregivers, only 2% had reported abuse they had witnessed to management (Cooper, Selwood et al. 2008). In addition Matsuda (2007) reports that over half of family caregivers who abused a person with dementia did not regard their behaviour as abusive. In this survey of Japanese adults, respondents were more likely to rate a behaviour as less abusive if conducted towards a person with dementia than the same behaviour towards elderly people without dementia. This then indicates that self report of abuse is likely to be unreliable due to perception as well as disclosure issues. There is, then, a clear need for tool(s) to identify actual or potential abuse independently of staff report.

Establishing a reliable set of tools for including the experience of abuse and neglect by people with dementia or other cognitive disabilities is vital in providing an evidence base for policy making in this area. However, there is very little that currently exists to help examine the prevalence of abuse and neglect for

those who are most vulnerable and who are least able to communicate that they are being abused or neglected. People with dementia and those with other conditions that compromise language and memory abilities are particularly vulnerable to abuse and neglect and are unable to use existing channels to complain or to report it. Existing research has utilised interview or survey methods, which exclude the possibility of including the perspective of those with the greatest levels of disability, and who are most vulnerable to abuse and neglect, from the evidence base to date.

Observational tools used to detect abuse and neglect

As there are no existing observational tools specifically designed to detect abuse, neglect and loss of dignity in relation to people with dementia, a review of the literature was undertaken to establish whether there were any existing observational tools developed for use with other vulnerable population groups looking at abuse and neglect. They might then provide a base upon which a tool for use with people living with dementia could be developed. Fulmer et al (2004) in their review of tools for elder abuse, critique the transfer of research from one population into understanding abuse and neglect in another, however, given the paucity of information on abuse of people with dementia this widely utilised approach is applicable if exercised with caution.

The three key population groups examined in the literature were children, older people and people with learning disabilities. Children and people with learning disabilities face many of the same communication and vulnerability issues that older people with dementia also experience and so whilst the groups are not directly comparable the findings from studies in these two groups may provide some useful context for this project.

The literature review was undertaken using the databases Medline, Psychinfo, Pubmed and Web of Knowledge and using the following key search terms in various combinations - abuse, neglect, observation, identification, child, elder, older, learning disability. Studies published between 2005 and 2010 were included. The following review summarises key components of observational tools and methodologies within each of these populations. We then draw out commonalities and make recommendations from this for design of an observational tool to detect abuse and neglect in people living with dementia.

Older people

The majority of studies where observation was linked to detection of abuse and neglect of older people, focussed on screening by practitioners within emergency, hospital, out-patient or other medical settings. This is normally in the context of being able to undertake physical examinations of the patient.

Fulmer et al (2004) undertook a review of progress to date in developing tools to screen and assess for elder abuse largely occurring at home. They assert that the literature generally suggests self report cannot be relied upon, with only 30% or less of identified cases of abuse being reported by the person being abused. They suggest brief instruments should be used in busy environments, with more in-depth tools being utilised in adult protection services. They also suggest a more in-depth follow up tool where initial screening suggests the potential for abuse.

Harrell et al (2002) surveyed US doctors and highlighted a number of key common elements they used when diagnosing elder abuse and neglect. These were always gathered through taking a medical history and undertaking a physical examination. From a history perspective most common things to find in patients who were abused or neglected were the rapport between the patient and their carer, their compliance with medication, assessments of activities of daily living and instrumental activities of daily living and loss of social activities. Physical signs included the general appearance of the patient, bruising or other injuries, nutritional status and dehydration.

These indicators are supported by other studies. Nadien (2006) reports that it is the quality and content of interactions between an older person and their family carer that indicate whether abuse or neglect will actually occur in relationships where older persons are vulnerable to abuse. O'Keeffe et al (2007) report that the effects of abuse on individuals can be significant and include emotional distress, loss of confidence and self-esteem, depression, social isolation and negative impacts on health. Wang et al's (2007) scale for assessing psychological abuse in older people include six observational indicators that include lack of responsiveness, facial expressions of dissatisfaction towards the caregiver, unexplained verbal aggression, and privacy not being respected.

Yaffe et al (2008) found that different health and social care professionals (social workers, nurses and doctors) had different attitudes and thus gave different answers to questions on an elder abuse detection tool. Furness (2006) asked care home managers and residents to identify what they saw as abuse or neglect. The main examples identified by the two groups were rough handling, speaking in an inappropriate or sharp manner to a resident, residents being left on the toilet or commode and physical abuse. This does not however, cover the full range of actions or inaction that might constitute abuse or neglect. Therefore, there is a clear need for training to accompany any observational tool to detect abuse and neglect to ensure consistency in rating of what is observed.

The implications of these studies for aspects that need to be included in an observational tool to detect abuse and neglect in people living with dementia are:

- Interaction/relational style/quality with staff – physical and verbal;

- Ability/disability levels (ADLs) compared with degree of physical disability and cognitive impairment;

- Availability/observation of amount of social activities, interactions and opportunities;

- Physical appearance of patient;

- Intake of fluids and food over course of day;

- Observe for residents being taken from communal areas to toilet and not returning for long periods;

- Resident who express significant levels of emotional distress;

- Residents seem to lack confidence, appear depressed and socially isolated;

- Poor resident health beyond what would be expected e.g. recurrent infections, significant levels of depression or pain.

Children

Children are vulnerable to abuse and neglect and in particular younger children experience similar difficulties in communicating their experiences as people with more advanced dementia. Therefore, studies on detecting abuse and neglect in children may offer some insight into indicators that may be applicable to people with dementia. Bousha and Twentyman (1984) examined the amounts and types of communications occurring between mothers and their children. Abusive and neglectful mothers interacted with their children far less, and were significantly less likely to initiate interactions or to engage in verbal and non-verbal affection and play with their children than mothers in the control group. Neglectful mothers were the least communicative. A similar communication pattern was found in the children. Abusive mothers showed the highest rates of verbal and non verbal aggression and both the abused and neglect children showed higher rates of verbal and non-verbal aggression than the control group children. Abused and neglected children are also more aggressive with their peers and neglected children engage in less interactions with peers than other children (Hoffman-Plotkin and Twentyman 1984). These findings are supported by Lykke et al (2008) in a study on GP detection of child mistreatment. They found GPs were often alerted potential abuse or neglect through a feeling of "this is not normal", which was produced by things such as the problems or symptoms a child was presenting with and the communication of the parent or the child during the consultation.

The implications of these studies for aspects that need to be included in an observational tool to detect abuse and neglect in people living with dementia are:

- Amount of interaction between staff and residents

- Amount of instructional behaviour from staff and residents

- Amount of verbal and non-verbal affection and fun

- Aggression from staff towards residents

- Aggression levels in residents

- Amount of interactions with other residents

- Amount of positive social behaviours observed in residents

- Behaviours, interactions etc just not appearing usual or normal

Learning disability

There is very little research conducted on people with a learning disability who have experienced abuse and neglect. There appear to be no observational tools that have been developed to detect abuse and neglect in those people with a learning disability who experience communication difficulties that mean they are unable to describe their experiences. This is supported by Peckham (2007) who states that often problem behaviour highlighted in referral letters to Clinical Psychologists indicates a past history of abuse or neglect. These behaviours are similar to those described in children who have been abused or neglected and include sexualised behaviour, anger and aggression and self harm.

Summary of the literature to use in tool development

Overall the majority of studies relate to identification of abuse and neglect by health and social care professionals working as individuals or through team assessments/reviews. The shorter assessment tools generally rely on talking to the person and/or their carer. More detailed tools take into consideration many factors and usually involve physical examination as well as detailed discussions with patients, carers and sometimes wider family, friends and other professionals. Where observation does take place there appear to be a number of common indicators that were taken into consideration in developing the tool.

The person being observed

- Amount of withdrawn/disengaged, depressed behaviours

- Amount of positive social behaviours

- Levels of emotional distress or aggression

- Responsiveness to care recipient to interactions from caregiver

- Facial expression of resident when interacting with caregiver

- Physical appearance

- Dietary and fluid intake over the day

Interactions with others

- The amount of interactions between the caregiver and the care recipient;

- The quality of interactions between the caregiver and the care recipient e.g. affection, fun vs aggression and negativity;

- Amount of interaction between people in the care environment.

General Environment

- Amount, opportunities for and engagement with social activities;

- Amount of and opportunities for engagement in activities of daily life;

- Privacy not respected through private tasks being carried out in public areas or without due care to ensure privacy;

- Locks on doors etc.;

- Other restraints to prevent movement e.g. getting up from a chair or movement to another place.

Conclusion

In designing a semi-structured interview format for our focus groups and interviews it was decided to utilise the three main headings of:

1. Person receiving care – in this case person with advanced dementia

2. Interactions – between care worker and care recipient

3. General environment – issues in how the physical world of the care recipient impacts upon them

Part 2: Gathering the views of expert stakeholders

Introduction

In order to ensure that the subsequent tool was grounded in current practice experience and in the lived experience of people with dementia and family members, we built on the evidence from the literature review in gathering the views of a variety of stakeholders. We defined stakeholders as people who have substantial experience and expertise concerning the factors that might indicate that abuse, neglect and loss of dignity are occurring or the factors that are protective of such occurrences. Thus the research team sought to obtain a wide range of views in order to fully inform the development of the observational process. Therefore the views of the following people were sought:

- People living with dementia(Focus group 4, FG4);

- Family carers (who have not experienced abuse) (Focus group 3, FG3);

- Family members whose loved ones have been abused (Focus group 1, FG1);

- Care practitioners with experience of working in abusive situations in the past maybe as "whistle blowers" (Focus group 5 and Interviews PI 1 to 6, FG5 and PI 1-6);

- Professionals with experience of investigating allegations of abuse (Focus group 2, FG2 and Interviews EPI 1-7)

It was felt to be particularly important to obtain the views of people living with dementia. Traditionally people with dementia have been marginalized from research and decisions concerning service provision and quality of care (Cantley *et al.* 2005, van Baalen *et al. 2011*). As Cantley *et al.* (2005) and others in this field highlight, with increasing acceptance of the concept of personhood and person centred care, this has become an untenable position. Nevertheless, involving people living with dementia presents particular challenges, to ensure that their voice is heard, within the context of the communication and cognitive difficulties experienced. Thus we sought to consider appropriate methods for inclusion of people living with dementia. van Baalen *et al.* (2011) indicate that the most effective means of gaining the perspective of people living with dementia on issues concerning quality of care involves either individual interviews or focus groups. Both methods have strengths and weaknesses and rely on the need for the researchers to adapt the approach they use in relation to interpersonal skills, autonomy, accessible and clear information, organisation of the group and ensuring safety (van Baalen *et al.* 2011). The growing body of literature, plus

our own experience in working with people living with dementia informed the approach we used to achieve representation from people living with dementia.

We used the literature to provide semi-structured guides to interviews and focus groups. Thus we asked:

When you visit a care home what signs make you concerned that a culture of care exists where abusive practice, neglect or lack of respect may be occurring?

- *What signs would you pick up from residents with dementia?*
- *What signs would you pick up from direct care staff?*
- *What signs would you pick up from others involved in the home?*
- *What signs would you pick up from the general environment?*

Alternatively, when you visit a care home what signs make you feel reassured that a culture of care exists where abusive practice, neglect or lack of respect are highly unlikely to occur?

- *What signs would you pick up from residents with dementia?*
- *What signs would you pick up from direct care staff?*
- *What signs would you pick up from others involved in the home?*
- *What signs would you pick up from the general environment?*

Method

Participant recruitment

Purposive sampling of participants occurred in a number of ways: through open invitation on our university websites, through an invitation to students registered on dementia studies programmes, through the Alzheimer's Society, through our care-homes networks and through our Safeguarding Adults contacts. Prospective participants were given information sheets and an explanation of the process, aims and outcomes for the research. They were provided with the list of questions above for consideration. Participants who agreed to take part were invited to complete consent forms for participating, for audio-recording where appropriate and for use of attributed quotes.

The focus groups and interviews

Semi structured interview guides were developed for interviews and focus groups incorporating pre-prepared questions that encouraged members' reflections on what constitutes abuse and neglect and what we would observe or not observe in care homes where abuse and neglect were present. We also

sought their reflections and opinions on the process of using an observational framework to detect these aspects in practice.

A three-stage consent process was used for participation in focus groups and interviews:

1. Agreeing to participate after receiving detailed information about the stakeholder group;
2. Attending the focus group on the allocated date and signing the audio consent form;
3. Attendance throughout the focus group. It was made clear to participants that they are free to leave at any point during the focus group if they wished.

It was expected that those people who returned the consent form had the capacity to make the decision to participate in the group. We nevertheless recognised that the process adopted needed to be adapted to ensure that consent from people living with dementia was appropriately achieved, and did not marginalize them, or indeed place them in a position where they felt they had to agree. Pre-existing contacts within the Alzheimer's Society were used to consider how such a group might best be achieved. A small group of people living with dementia, who were living at home, had already participated together for other purposes, as a focus group, which also included commenting upon issues concerning quality of care. They were continuing to meet together on a regular basis and had indicated their desire to continue to be involved in such work. The member of staff within the Alzheimer's Society, who was facilitating this group, discussed with them whether they would be interested in an approach from us.

They agreed to this and JLF went to meet with them and discussed the research, using clear and specific information sheets plus a summary of the discussion. They agreed that we could carry out the focus group with them. The meeting was arranged at the venue they usually use thus facilitating safety and familiarity. They were asked whether they wished the member of staff who usually works with them to be present, they identified they would like this, so she sat outside the group but in the same room. JLF and TP facilitated consent at the beginning of the meeting, explaining the research again and emphasising their right to refuse to participate or withdraw at any point. Those participating in this focus group did not have such significant cognitive problems that precluded them from giving informed consent.

The questions used in the focus group for people living with dementia were adapted to ensure that they were understood, so participants were asked about their own experience of visiting people living in care settings, and what might be considered abusive or neglectful care, and what might be positive care.

All focus groups were audio recorded and detailed notes were made during the group itself. Participants provided formal consent for the audio recording prior to the stakeholder meeting commencing. Focus

groups were facilitated generally by two researchers led by JLF. JLF is experienced at leading focus groups. Some were held at the university, others in venues that were appropriate to the needs of the participants. Care was taken to create a supportive and relaxed environment where people felt comfortable to contribute.

At the commencement of the focus group meeting there was the opportunity for introductions, explaining the nature of the groups and answering any questions. Given the nature of the discussions we recognised that there was a risk that participants may have found some of the discussions upsetting or distressing. JLF's long experience as a mental health nurse and as an Admiral Nurse equipped her to deal with these situations and to handle the discussions with sensitivity. Support for participants was made available after the focus group was completed if needed. Focus groups were scheduled to last for around 90 minutes.

Focus group participants were asked to ensure that where possible anonymity of persons and organisations was maintained when discussing personal experiences.

It was originally intended that focus groups were the sole source of data collection. However, a couple of issues influenced the need to provide the opportunity for individual interviews. Firstly, during the time that these focus groups were carried out, significant snow fall resulted in one group being cancelled as participants were unable to reach the University. Given the tight timescale, it was felt to be appropriate to carry these out as telephone interviews. Secondly, some participants were happy to take part in the study, but the distressing nature of the topic under discussion meant that they preferred to do this on a one to one basis.   Similar guiding principles were followed regarding the interviews. Interviews with professionals were usually conducted over the telephone at a pre-arranged time and usually lasted between 45 to 75 minutes. Those who were interviewed followed the same consent procedure and the same set of guiding questions.

Analysis

Data obtained from the interviews and focus groups was transcribed and anonymised. Three researchers (one of whom had not been involved in data collection) carried out a line by line thematic analysis (Ryan & Bernard, 2003; Braun & Clarke, 2006). It was evident during analysis that there were some differences between data achieved in focus groups and interviews, in that focus groups provided opportunities for members to further explore and drill down to the key issues of concern, nevertheless there was considerable consistency across focus groups and interviews in regard to their perspectives on the themes identified. Thus, key themes and sub-themes that illustrated the factors that participants highlighted would need to be incorporated into an observational process to detect abuse and neglect were identified.

Analysis was therefore inductive, derived from the participants' transcripts, and deductive, derived from the literature and the researchers' prior knowledge and practice. It was not our intention to carry out a full and in-depth thematic analysis in which hierarchies of themes are identified, but rather to identify the breadth of indicators of abuse, neglect and loss of dignity, or the indicators that are protective of such occurrences. Thus the results achieved during analysis represented the most commonly occurring indicators identified by participants. These indicators were subsequently used to inform the development of the pilot process, including the manner in which observations should be carried out, the process and the structure of such observation.

Results

Overall people were happy to be involved in the focus groups. Although some of the discussions were sensitive most reported feeling positive about taking part. Participants reported finding it validating to share their experiences with others in a similar position. Participants were motivated by a wish to see a reduction of poor practice in relation to people living with dementia.

We undertook five focus groups and 13 telephone interviews (**Table 1**).

Table 1 Participants in Focus Groups and Interviews

Type	No. of Participants	Stakeholder
Focus Group 1 (FG1)	4	Family Carer (person in care home experienced abuse)
Focus Group 2 (FG2)	4	Professionals with experience of investigating abuse
Focus Group 3 (FG3)	3	Family member of person in a care home (not experienced abuse)
Focus Group 4 (FG4)	4	Persons living with dementia (not living in a care home)
Focus Group 5 (FG5)	8	Professionals with experience of whistle-blowing/ investigating abuse
Interviews (EPI 1-7)	7	Expert Professionals with experience of investigating abuse
Interviews (PI1-6)	6	Professionals with experience of whistle-blowing/ investigating abuse

Four of the focus groups and three interviews were recorded and transcribed. A further 9 interviews and one of the focus groups used written recordings. The 5th focus group was carried out after the initial process was developed to explore their views on the framework we were proposing.

Identified themes were organised into categories informed by the questions asked during the interviews and focus groups. Participants were asked to consider what indicators might lead them to believe abuse,

neglect or loss of dignity was occurring. They were also asked to consider the indicators that would suggest that abuse, neglect and loss of dignity were unlikely to occur. These were further broken down into considering indicators regarding the person, the care staff and the environment within which they live. The themes that emerged are grouped in the same way here; that is themes to do with the person, themes to do with interactions and themes to do with the general environment.

Person; Observations of negative signs

Indicators of the presence of abuse, neglect and loss of dignity for the person living with dementia spanned a range of physical and psychological and behavioural indicators. Themes of poor physical care, overt distress, anxiety and withdrawn behaviours were prominent. These are represented in **Table 2.**

Table 2: Observable Indicators of Abuse, Neglect and Loss of Dignity: in the Person living with dementia

Physical Indicators	Overt distress behaviours	Agitation & anxiety	Withdrawn & disengaged
Physical appearance not maintained/unkempt (PI4/FG2/EPI4)**	Behavioural extremes (FG2/EPI6)	Watchfulness (FG2)	Disengaged (FG4)
Physical Injuries (FG2)	Unattended distress (FG2/FG3)	Agitated around certain people (EPI4)	Interactions withheld around certain people (PI4)
Physical stress (FG2)	Calling out (unattended*) (FG1/EPI1)	(*Unattended) Distress/anxiety (EPI1/FG3)	Unattended withdrawn behaviour (FG2/FG3/EPI5)
Withdrawn/low energy (PI4/EPI2)	Perceived high levels of challenging behaviour (EPI6)	Agitated (FG2)	Passive (PI2)
Sleepy/ Sedated (EPI1)	Residents harmful towards each other (EPI3)	Wary/fearful (EPI3/PI4)	
Dehydrated/Nutritional Intake (FG1)		Tension (EPI3)	

* Unattended refers to participants view that the behaviour itself could be cause for concern but was more problematic if not responded to by staff.
** see Table 1 for key

Physical Indicators

A significant number of the participants suggested that there are physical indicators that could be observed. These indicators included the state of someone's appearance and physical well-being and whether their need for cleanliness and individuality had been respected and responded to:

> *"Would never sit in crumpled, dishevelled clothes... uniformity in dressing" (PI1)*

> *"Someone with their skirt tucked in their knickers, it shouldn't happen" (FG2)*

> *"We've found people with dried food on after a meal, one lady in particular like that and she was quite upset... she had always been used to shopping at quite a high boutique and having really nice clothes on, she was wearing jogging bottoms and... she was distraught because of the clothes she was wearing and had food stains down her" (PI4)*

> *"If we have got people, more than one person in dirty clothes, and we've got people with torn fingernails, dirty fingernails, long fingernails" (PI5)*

> *"So I say to [staff] either this lady or this lady, one of them has the biggest problem and really needs sorting out; would you deal with it? [he said] yes. That was about 10am, at 12.45 I'm walking [relative] down to lunch and [staff] is sitting in the lounge feeding somebody, so I go "[staff] did you sort it out?" He said nah. So I asked why not... So he said we change them after lunch" (FG1)*

Whether there was evidence of physical injuries such as bruising, cuts and abrasions:

> *"I think facial injuries are more likely to be indicative, I don't think they're an indication of physical neglect on the part of the carer, but it is neglect because they are evidently walking around unstable and unsupervised and banging into things" (FG2)*

> *"Maybe an inordinate number of people with injuries on their shins, where they've been pushed in wheelchairs without footplates" (PI5)*

And signs of physical distress:

> *"I would be looking for physical stress in relation to symptoms like breathlessness, not being positioned in a way that facilitates breathing, great care, slow management of anything physical like washing. Is it managed carefully, are they in pain when moved, facial expressions, sounds they might make" (FG2)*

Physical indicators also included evidence of sedation, sleepiness and signs of withdrawal relating to low energy levels:

"Do they look alert or sleepy, possibly in mental or physical ill health or possibly sedated" (EPI1)

Finally nutritional and fluid intake was also considered as important:

"He was clearly dehydrated – his skin changed in a very short amount of time" (FG1)

"Full plates left in front of her with cold food on it, nobody ever fed her, medication she didn't have" (FG1)

Overt distress behaviours

A significant number indicated that there may be high levels of behaviour which is perceived as challenging in response to impoverished care environments, again, with some recognising that this is particularly concerning when not responded to or inappropriately responded to:

"Overt shouting or screaming" (EPI2)

"His trouser pockets were totally destroyed where he had been ripping away, huge agitation" (FG1)

"Challenging behaviour, even though in the best settings these occur, it's when this is expressed but not attended to. There are no attempts at amelioration, or responses are not appropriate or early enough" (EPI6)

Anxiety and agitation

A significant number of the responses involved observation of anxious or agitated states as being indicative that all was not well. This was particularly if people were unattended for period of time in levels of high anxiety. Sometimes these were verbal expressions of distress, but more commonly related to non-verbal indicators of distress.

Such indicators included unattended distress, recognising that while expression of distress does occur in positive care environments it is responded to in a timely and appropriate way:

"I think ...if you see somebody sat there crying for help and nobody is even speaking to them, that gives you the impression that all is not right" (FG1)

"We might see distress in someone's face, the way someone is moving or the way someone is articulating and shouting, and to not acknowledge that would seriously worry me" (FG2)

Some participants highlighted the importance of observing for non-verbal indicators such as wariness which is manifested in watchfulness, tension, halting of communication and changes in posture:

"When a resident is sitting in the chair and staff are walking by, you can tell that some residents can be very wary of certain staff and someone that's been chatting quite freely will suddenly shut up when a certain member of staff comes by – you can see a change in that resident, you can sense that they are uneasy in that environment" (PI4)

"Sometimes it's really subtle body language that on its own it's difficult to say what it's about. But almost that watchfulness, sometimes even fearful, but certainly watchfulness. Almost like somebody is taking a deep breath when somebody approaches them, a kind of cowering" (FG2)

"People who aren't relaxed and are tense with some people and in some environments" (EPI3)

A number of participants mentioned fearfulness:

"After 3 weeks he was not mobile, he was terrified" (FG1)

"He kept flinching all the time and kept saying 'sorry, sorry, sorry' all the time" (FG1)

"Fearful reactions to staff interventions, flinching when approached by staff" (EPI6)

Withdrawn Behaviours

Similarly, many participants raised concerns about withdrawn behaviour:

"Very withdrawn, very sleepy, sort of given up really" (PI4)

"People being very passive I have noticed as well in contrast to the aggression, people become very passive to the situation in cultures where poor care happens" (PI2)

"Residents not looking up, not looking at me, faces with 'no hope' in their eyes. Not about their frailty but the lack of hope in their eyes" (EPI2)

With some emphasising the importance of this being unattended withdrawal:

"So I would be concerned if they were sitting in their seat and it was obvious that nobody had come to engage with them for a very long period of time... I would have thought that a good hour would be a long time" (FG3)

"I think a worry is – especially when you've got some quite loud people – is that the passive ones are totally ignored because they're quiet" (FG3)

Person; Observations of positive signs

Indicators that may suggest that the person is protected against the risk of abuse, neglect or loss of dignity were identified by participants as spanning a range of physical, emotional and behavioural factors. These are represented in **Table 3.**

Table 3: Observable Indicators of positive signs that the environment is protected from Abuse, Neglect and Loss of Dignity: in the Person living with dementia

Physical indicators	People being themselves	Relaxation	Engaged with the world
Resident's appearance maintained (EPI1/EPI5/EPI6/PI4)	Residents communicating with each other (EPI1/EPI7)	Uninhibited behaviour (FG1)	Residents do not fear contact (PI1)
	Individualised activities (PI1)	Relaxed & gregarious Person with dementia (PI2)	Not withdrawn (FG1)
	Freedom/autonomy of actions (FG4/EPI7)		Involvement/empowerment (PI4)
	Identity affirmed (EPI)		Residents engaged (PI1/EP2)
	Continuity of Self (FG4)		Meaningful activity (PI4/EPI1/FG2/PI5)
			Engagement/opportunity for engagement (EPI4)
			Residents engaged with meaningful activity (PI1)

Physical indicators

There were far fewer comments about the positive signs that would be observed to do with physical health and well-being although there were some about peoples' appearance being cared for. This links to the importance placed on maintaining identity and continuity of self and included such factors as the personal items of clothing, jewellery or makeup valued by individual residents:

> *"People have different jewellery on or someone might like to wear beads and has got them on; rather than everyone's nails painted in a bright red – because everybody has had a manicure" (PI4)*

But was also more generally referred to in terms of the personal care people received:

> *"Their physical appearance for example hair and nails are cared for, and they receive good oral care" (EPI6)*

People free to be themselves

Participant's responses in this section highlighted the significance of the level of personal control and autonomy supported within the environment. Participant's living with dementia indicated that freedom to

choose what one wished to do, and the autonomy to carry this out was an important indicator of a supportive care home:

> "And if people want to go outside, yes they should have the ability to do that for exercise" (FG4)

> "if there is a garden behind the place then perhaps they would like to have a little potter in there. It would be nice to think that they would be allowed to do that" (FG4)

This was also reinforced in other participant's responses:

> "Free to move about and touch things and move things" (EPI7)

> "Empowerment of people with dementia to get involved in activities, restoring peoples citizenship, giving something back to the care home" (PI2)

Participants also emphasised that maintaining the identity of residents, thus ensuring continuity of self was a fundamental aspect of prevention of abuse, neglect and loss of dignity:

> "Being treated as an individual, who they are now, who they have been in the past, their identity now and then" (EPI4)

> "If I had been an outside sports man I would like the opportunity to do some sport, maybe I've been bowling or maybe I've been a sailor, once a week I would like the opportunity to continue doing that. Maybe it is the responsibility of the organisation that you're with, there is a question of responsibility" (FG4)

Engagement

Just as disengagement and withdrawal were seen as negative indicators so engagement was viewed very positively and frequently mentioned by many. Participants highlighted that positive care environments created opportunities for residents to join in activities that were meaningful to them:

> "there appears to be less confusion, a lot more people have smiles on their faces, are happy to join in, caring for others, are happy to enjoy a good sense of humour" (PI2)

> "Seeing activity and people being occupied... Are there things to do?" (EPI4)

> "Its age appropriate activities – age is the wrong word – appropriate the that person's life experience" (FG2)

"Engaging people with the normal day-to-day activities of the home... They got her involved in things that were about doing things she would have done, it turned into a very positive experience for her, and them. It's about normal activities" (FG2)

That this meaningful activity was individualised:

"there was an individual approach to what people might want to do in terms of activities, supporting people to go and find something to do, but on a very individual basis – bringing photo albums out, bringing knitting out, those kind of things that were very personal to people in the lounge" (PI2)

And that there were opportunities to engage in self directed activities, that were relevant to the person's history and identity:

"Meaningful activity doesn't have to involve a member of staff" (FG2)

"Residents engaged with setting the tables, folding napkins, if you've got somebody who is further down their journey of dementia, maybe they're being back when they were an accountant and they've got props so they might have pencils and paper – real simple stuff but stuff that gives them a sense of identity, belonging and purpose" (PI5)

Participants highlighted that the level of engagement of residents was also a noticeable indicator of well-being and thus a protective factor:

"Mobile, lively and not all sitting around and sleeping. Increased levels of activity and engagement" (PI1)

"Residents who are engaged, concentrating and looking purposeful from their perspective" (EPI2)

Including that residents are likely to be engaged with each other and others within the care home environment:

"Lots of interaction in an environment that is managed to facilitate this by ease of staff working within the environment and residents being able to communicate with each other" (EPI1)

"People talking with each other and staff – it may not be a logical conversation but they are interacting with others" (EPI7)

Additionally, that residents are able to express themselves freely:

"I think bursting into song is one thing that you sometimes experience with some people, that's not going to happen when they're not feeling comfortable" (FG1)

"To me if you've got and old iron and an old table and a load of old shirts in a basket, that's great so you just let people wonder around and do whatever they like, so they might actually put the iron underneath the chair thinking it's a car going into a garage or whatever they're thinking in their head – who cares – if they are allowed to do that, they might put the shirt on, or they might rip the shirt up, or they might bundle the shirt up and put it in their bed – who cares" (FG1)

Interaction with staff; Negative observable signs

Analysis of the transcripts yielded some data which reflected characteristics in staff that are unobservable and thus not relevant for the purposes of this study, e.g. whether staff had received appropriate training or not. The current study sought primarily to focus upon the resident's experience. Accordingly, the transcripts were analysed with respect to the interactions experienced by residents. A number of types of interaction were identified that participants felt might be observed in an impoverished care environment. These are represented in **Table 4**.

Table 4: Observable Indicators of negative interactions as signs that residents are at risk of Abuse, Neglect and Loss of Dignity

Depersonalising	Ignoring	Control by staff	Overt disrespect
Individuality not acknowledged (FG2)	Talking over residents (PI4/PI1)	Intimidation in communication (verbal and non verbal) (PI4/PI1)	Use of inappropriate terms in interaction (EPI6)
Not explaining interventions to residents (PI4)	Low staff-resident interaction PI2)	Staff manipulation/holding power (FG2)	Negative emotions expressed towards the person by staff (FG1/EPI3/PI1)
Not recognising/or giving residents choices (FG4/PI4)	No communication during intervention (PI2)	Discouraging freedom (PI4)	Labelling/Objectifying residents (FG2/FG3/PI4/PI3)
Unaware of resident's capabilities/needs/history (FG1/PI1)	Unattended distress (FG 2/FG3/PI4/PI2)	Giving orders rather than choices (FG1)	
Lack of empathy/understanding (FG3/PI1/EPI3)	Un-attended withdrawn behaviour (FG3/PI4/PI2)		
Don't explain actions to residents (EPI 1)	Ignoring resident's requests (PI4/PI2)		
Outpacing residents (FG2)			
Task Focused Interaction (EPI7/EPI4)			

Indicators highlighted by participants were mainly related to interactions between staff and residents.

Depersonalising

Impoverished interactions were described as involving a lack of understanding of the needs, abilities and history of the person living with dementia:

> "A younger person with dementia - had always worn his hair long and the care home staff tried to have his hair cut" (FG2)

> " When my colleague and I have spent a bit of time we have managed to get a discussion going and staff have said oh I didn't know she could speak, I didn't know she could get a sentence out"(PI4)

"They obviously haven't got a clear idea about how she can function, by the very fact that they can have this conversation this many hours later because of cold food sat there. Clearly she couldn't feed herself" (FG3)

The focus of staff interactions was also raised by participants:

"Interactions between staff and residents, where they are very task focused" (EPI4)

And where interactions involved outpacing the resident

"When someone needs the toilet, it's not that they're being inappropriately dragged but being rushed. You can tell because the resident starts to shuffle, they're quite evidently walking too fast for them" (FG2)

Participants also highlighted concerns about the quality of the interaction during direct care, suggesting that staff would not give explanations about what they wanted to do:

"Sometimes you get staff - especially with people that have given up – they will just come and put a pad around someone without speaking, without letting them know that lunch is approaching, what would they like?" (PI4)

"Where people were just pushed in a wheel chair without making it an interaction – seeing that one time is ok, but it was the culture and nobody was questioning it" (PI2)

Ignoring

Ignoring the resident's attempts at communication was frequently mentioned:

"I have had incidents where staff are trying to get people to eat food – again they're on the verge of forcing someone when they're clearly indicating that they don't want something with shaking their heads and clenching their lips, when staff aren't picking those signs up or are ignoring that" (PI4)

"Other times we found staff ignoring people when they ask for things" (PI4)

Or that the staff would talk over residents:

"Zoom in and start doing without engaging the person" (EPI4)

Or that staff would avoid interactions with residents unless necessary to complete a task:

"Staff who talk to each other a lot but not to the residents" (EPI7)

"But they're left just screaming, moaning, and of course that is extremely distressing. Sometimes there are ten in the lounge and not a nurse in sight" (FG1)

Control by staff

Controlling interactions in which staff overpowered residents wishes were described:

> *"People being told to sit down, people being in their chairs the whole time frightened to actually stand up" (FG1)*

Or to control their access to meaningful and enjoyable experiences:

> *"There was a lot of manipulative behaviour between the staff and the smokers about when they could have them and when they were allowed to smoke" (FG2)*

Participants indicated that this also involves the use of intimidation verbally and non-verbally:

> *"Someone is trying to get up out of their chair and it's how they're encouraging, sometimes verging on forcing someone to sit down" (PI4)*

> *"Standing over residents in an intimidatory fashion" (PI1)*

Overt Disrespect

Participants' perspectives included that negative emotions experienced by staff were evidenced in their direct interactions with residents:

> *"A bit snappy and short tempered, she would shout 'oh shut up'" (FG1)*

> *"Do staff respond impatiently if they are cross?" (EPI3)*

And labelling or objectifying people living with dementia:

> *"the manager of the unit, when we got there to collect her, had said that she had called staff in from all the other parts of the building to come and look at this 98 year old woman who was physically attacking people with her walking stick, I just couldn't believe that 1) they had done that and 2) they had said they had found it quite funny – that's my [relatives] dignity"(FG3)*

> *"So the manager said she would tell me which residents I could speak to, we went down to the room and she said 'she can talk, she can talk, she can talk, she can't talk'" (FG2)*

And show a lack of empathy or understanding for the resident's emotions and experience of the world around them:

> *"One of the care staff had gone up to her and she'd called her a bloody monster or something, so this young girl who was paid to care screamed and ran off giggling to her sister saying 'oh*

she's just called me…' I sat there with my mouth wide open and I thought that is just horrendous" (FG3)

Power

The use or misuse of power was illustrated through exploration of interactions between staff and people with dementia in the focus group with people living with dementia. Participants reflected upon the importance of being offered choice and the manner of approach from staff, and as a consequence, the level of personal control they would be able to achieve:

"I don't eat gravy, if anybody put gravy on a dinner for me … I wouldn't eat it, I wouldn't eat any of it … ask us anyway rather than just slap it in front of you" (FG4)

"When I last went into hospital … the first thing [the staff] did was to tell me what the routine was, that way… you as a person know what is going to happen" (FG4)

In one of the focus groups for family carers, participants also reflected upon the misuse of power by staff to control residents through verbal and non-verbal interactions:

"Walking along this long corridor and there is absolutely no noise… and you think why is there no noise going on, what's going on here? And you go in there and people are sat, my (relative) is sat at the table with his back to everybody else and there is another man sat, two men on each table. There is absolutely nothing to do, they're both hunched forward over the table, everybody else is sat round in chairs, there is absolute silence, the woman who is the carer with them… was sat there facing out to look at all the people who were all sat … hunched shoulders, heads down. [The carer] was sat like this and had a look of fury on her face… There was total silence and the air of menace was huge, absolutely huge. I sort of went 'well hello, what's going on here then?' and she's like 'they've all been misbehaving'" (FG1)

These perspectives were echoed and expanded in the interviews and focus groups with professionals. For example the use of power in controlling the physical environment was illustrated through the positioning of furniture and objects:

"Are they able to get around and walk freely or are their seating or environmental arrangements stopping this. Sitting in a chair that is inappropriate for them, chairs too big or too small. Chairs placed neatly and subtly in front of tables so the person cannot move" (EPI1).

Additionally the use of power to enable and facilitate resident independence:

"People with dementia have personal stuff with them and are involved in doing the laundry, doing things in the office, unloading the van and being part of the home" (PI1)

Interaction with staff; Protective observable signs

As with the indicators associated with the risk of abuse, neglect and loss of dignity, some of the participant responses highlighted characteristics that would not be observable. Thus this section focuses on those indicators that are protective of abuse, neglect and loss of dignity that are observable. These are represented in **Table 5.**

Table 5: Observable Indicators of positive interactions as signs that residents are protected from Abuse, Neglect and Loss of Dignity

Personal Identity	Inclusive	Supportive	Warm
Individualised activities (PI2)	Communication during interventions (PI3/FG3)	Staff responsive & supportive (EPI5)	Staff personally invested (FG1)
Knowledge of the person (FG1)	Social interaction/company with staff (FG1)	Equality within interaction (EPI2)	Attentive staff (EPI1)
Staff knowing resident, individualised approach (FG2)	Relationship interaction (PI4)	Staff supporting/enabling Resident's choices/autonomy (PI5/PI4)	Staff patience (FG2)
Identity affirmed (EPI4)	Same level/explaining during interactions (EPI2)	Eating – Positive/appropriately supported experience (EPI1)	Well-being focused (PI2)
Staff knowledge of residents (EPI5/EPI6/EPI4)	Explaining actions (FG3)	Distress/'Challenging behaviour' skilfully attended (EPI6)	Staff Warmth in interaction (PI4/EPI6/EPI4)
Continuity of self (FG4)	Social interaction (PI4)	Maintaining/increasing capabilities (FG1)	
Individualised approach from staff (PI1)	Staff Interaction (FG3)	Going down to somebody's level (FG1)	
Understanding/knowing the person (PI4)	Staff interaction is individualised (SGI 6)		
Recognising individuality (FG3)	Staff appropriate interacting/touch/engaging with residents (EPI7/EPI6/EPI1/FG3/FG4)		
	Residents interacting with staff/residents (PI5/PI3/EPI7)		
	Social engagement staff/resident (FG2)		
	Staff/resident social interaction (FG4)		
	Staff/resident interaction (PI2)		
	Staff/resident integration (PI3/PI5/FG4)		

Personal Identity

Participants' responses reinforced the importance of interactions which focused upon maintaining the well-being, identity and abilities of the resident. Thus participants indicated that treating residents as individuals was important:

> *"I would be observing staff interaction and that they are treating people as individuals and not herding people around like cattle or like kids in school" (FG3)*

> *"there are people who allow time to look after emotional well-being as opposed to just the physical task of care, and promoting a good emotional well-being as well as just the physical tasks" (PI2)*

As was the extent to which staff knew residents and used this knowledge in their interactions with residents, thus maintaining their identity and sense of self:

> *"Good staff know peoples life history, they will come in the room and put the old musical records on because they know that [resident] used to be in the amateur operatics and loves them, those sorts of things they know to link in with their past" (FG1)*

> *"I watched a member of staff come into the room with a gentleman who liked a particular sort of music, she went over to the stereo, put a record on that he like, put a record on that he liked, and danced with him and she danced him to the toilet, I just thought 'wow'. It was so responsive to him" (FG2)*

> *"'In fact, the use of a pet name might be appropriate given your relationship with that person. Touching someone might be appropriate; it's those things that can be really positive" (FG2)*

Thus the delivery of care is individualised:

> *"You need to be talking to the person, not just shovelling spoonfuls of food into their mouth" (FG3)*

> *"The better homes will show different plates of food, do it slightly differently – the person might have been offered a choice verbally, is that appropriate to that individual?" (PI4)*

Inclusive

Participants also focused upon the skills of staff in interactions with residents, identifying a number of characteristics which they believed supported positive interaction, for example in posture and approach:

> *"She was very appropriate, she went round and came down to the level of everyone, she was doing all the things you want people to do" (FG2)*

And the use of humour:

"Sharing humour, you can tell instinctively when someone is laughing with someone and when they are laughing at someone" (FG2)

And the effective use of communication to explain what is going to happen:

"I think that it is also about staff taking time to explain things to people properly'' (FG3)

And that this relationship is often demonstrated through actions including making time to be with residents:

"You'll get [staff] the good one, who will pick up her files and go and sit with someone that is bed bound and do her, at least they've got some company" (FG1)

"There is one woman there who does a lot of shouting, and when she starts shouting the care worker will go up to her and say 'right *** what's the matter?', go and sit by her, quieten her down and she's fine for another couple of hours" (FG1)

Participants also felt that one of the indicators is related to the level of interactions between residents as well as between staff and residents:

"Lots of interaction in an environment that is managed to facilitate this by ease of staff working within the environment and residents being able to communicate with each other" (EPI7)

Overall these indicators seemed to be reflective of integration between staff and residents, rather than an 'Us and them' approach:

"Interaction with staff which shows that care staff are communicating with residents as fellow human beings, i.e. banter and chat" (EPI2)

"Staff eating with residents in the dining room" (EPI1)

"Staff approaches are more likely to involve communicating with people with dementia, not leaning over them, rather getting down on their level" (PI3)

"Care staff sitting down and being with residents, having a cup of tea with them, not rushing around, trying to get onto the next task, ignoring the residents on the way" (PI5)

Supportive interactions

Additionally supporting the resident to maintain their autonomy, abilities or skills:

"One lady actually went out in the snow, even though staff were absolutely terrified, this lady really wanted to go out and had always go out... that's respecting that person's want to do that and it spoke volumes to me because it's not often that people would be allowed that risk" (PI4)

"Being really patient, waiting while the person slowly gets out of their chair" (FG2)

"She withdrew and never came back until she went into this nursing home and she very slowly came back. [Did she remain incontinent? Or did they get that back?] They got that back actually. She's into a routine now" (FG1)

Warmth

Participants also indicated that this was demonstrated through the use of touch:

"they will go up to her and ...they will give her a hug" (FG1)

"Most staff in residents areas with residents, talking interacting gently touching, involving people in tasks" (EPI7)

Participants identified the importance of the relationship between staff and residents, highlighting that reciprocal relationships are in evidence in positive care environments:

"I have already mentioned the fact that I would like to have the regular information so I know what is happening. The other thing would be a good contact between yourself and the staff" (FG4)

"When she went into the home, she went in with the teddy as well, since then the staff in there have with their own money bought her 5 teddy bears. You wouldn't expect that" (FG1)

 "I know it sounds weird and not something that you can put in an academic way but staff feel that they and the residents are family; it makes a huge difference" (FG1)

"Being spoken too nicely, a little chat perhaps, the odd chat no and again, when I am sitting down a little chat for a short while – just a general" (FG4)

"she actually goes in on her day off, even if she's got a week's holiday she will go in for a couple of days to actually bath two guys that she always baths, because they don't like anybody else doing it – people don't do that if staff aren't happy"

"He asked the same questions about 3 times, each time she so patiently responded, so warm with him, there was a bit of touch there on his hand, not too much but that he felt comfortable with, and he responded and warmed to her and he smiled, and afterwards she said 'do you fancy a walk round the garden', that was so positive" (PI4)

And focused upon relationships as well as the care needs of residents:

> *"Responsive to requests not just task focused" (EPI1)*

> *"There was warmth there – in the better homes that's what we find – you can't sometimes put your finger on it but you can, we always have a joke in that you can feel the love in the home; it's that warmth and recognition and a mutual recognition around the team" (PI4)*

Such relationships between staff and residents also included staff being able to respond appropriately to the distress experienced by residents:

> *"Maybe evidence of challenging behaviour but this is responded to in an appropriate way and early enough to reduce the impact" (EPI6)*

> *"Reaching out to residents who are in distress" (EPI6)*

General Environment; Observable signs of abuse, neglect and lack of dignity

Indicators of abuse neglect and loss of dignity in this context were considered in relation to the physical environment, with participants indicating a range of factors that were in evidence, which would directly impact upon the experience for the resident living with dementia. These are represented in **Table 6.**

Table 6: Observable Indicators of negative environmental signs that residents are at risk of Abuse, Neglect and Loss of Dignity

Uncared for	Restrictive	Impersonal
Odour (EPI6/EPI4/EPI2)	Restricting freedom to move (PI2)	Noise Levels (EPI6/EPI5/FG1)
Decoration (PI1)	Tables/chairs used as restraint (PI2)	Lack of facilities to encourage self-care (PI1)
Cleanliness (EPI6)	Privacy not provided for (PI4)	Lack of objects and personal items for stimulation (PI1/EPI1/FG1)
Environment not cared for (PI4)	No selection of TV/radio programmes (EPI1)	Lack of availability of individual personal care items (PI4)
	Locked doors (EPI1)	
	Facilities available but not used (FG1)	

Uncared for

A number of participants expressed concerns about the odour and the general appearance of the environment.

> *"My eyes smarted with the smell of urine in there" (FG1)*

> *"Smell of urine, and/or smells stale equals lack of pride and can be the slippery slope" (EPI2)*

> *"Then there is the other extreme where a home is very unkempt and where residents are sitting in chairs that are full of dried food and are very grubby... we have found in our experience that staff will make up beds that have urine dried in, dry faeces in the bed" (PI4)*

However, others also mentioned that an excessive level of attention to cleanliness and/ or decoration to the building could also be a sign of an impoverished environment, for example:

> *"We've had two new homes open in [area] and they are palatial, but the standard of care..." (FG2)*

> *"A very glamorous environment but cleaning takes precedence over residents care" (PI4)*

Impersonal

Indicators in relation to the physical environment included the level and type of noise occurring. A number of participants highlighted the extent to which the noise levels reflected a peaceful and comfortable environment or one in which there were high levels of noise, often from inappropriate television or radio programmes, which did not seem to be turned on with residents' needs in mind:

> *"Often it's on daytime TV or Jeremy Kyle in the morning without recognising the impact that this might have on residents. The tone of Jeremy Kyle is confrontational and there is not recognition of the type of stimulation or impact of the stimulation" (PI1)*

> *"Is music on that's inappropriate for the residents' choices" (PI3)*

> *"There isn't any soap in the person's bedroom, no toothbrush, no way of carrying out any oral hygiene" (PI4)*

Finally, in this section, participants raised concerns about the lack of opportunities available for participants to achieve meaningful activity and occupation:

> *"Nothing around to stimulate, no access to activities, books, radio, photo's, pictures, cared for in a cold, bare, institutional environment" (EPI1)*

> *"There isn't a lot of stimulation around for people" (PI4)*

Restrictive

The participants additionally mentioned the extent to which freedom of movement was restricted in the care home:

> *"I always have concerns about when all the bedrooms are locked; it's usually when [staff] have one or two people who will go into bedrooms" (FG2)*

> *"Can people get outside easily" (EPI2)*

This also related to the extent to which chairs and furniture were used as restraints, or to prevent freedom of movement:

> *"Are they able to get around and walk freely or are their seating or environmental arrangements stopping this" (PI2)*

> *"How does anybody in a wheel chair, on a Zimmer frame, or a walking stick actually manage to open their door to be able to leave their room when they wish to?" (FG2)*

A further concern for participants was the extent to which the environment did not respect privacy or personal care needs:

> *"If you see that curtains don't even meet in the window, there is no privacy there; people don't even think it's important" (PI4)*

Or that facilities were available such as an appropriately designed garden, but not used:

> *"A garden, beautiful summers day, garden outside all properly laid out for people with dementia, not used" (FG1)*

General Environment; Observable signs protective of abuse, neglect and lack of dignity

The participant responses in this area focused upon indicators of an environment that was supportive of residents needs from a physical and psycho-social sense. Many of the indicators within interaction therefore overlap with those of the psycho-social environment. The specific indicators relating to environment are represented in **Table 7.**

Table 7: Observable Indicators of positive environmental signs that residents are protected from risk of Abuse, Neglect and Loss of Dignity

Stimulating	Enabling	Personalised
Opportunity to engage with possessions/objects (FG2)	Residents in 'staff areas' (FG2)	Own possessions (FG4)
Opportunity to engage with the world (FG2)	Protective technology (FG2)	Personalised environment (EPI2)
Meaningful activity (PI4)	Facilitating autonomy/freedom (PI4)	Individualised environment (PI1)
Opportunity for engagement (EPI2)	Environment supportive of needs (PI1)	Environment individualised (EPI7)
Engagement/opportunity for engagement (EPI4)	Staff maintaining supportive environment (EPI1)	
Environment with opportunity to engage (PI1)	Staff/resident integration (PI3)	
Opportunity to engage senses (FG2)	Positive structural environment (FG1)	
	Enabling environment (PI4)	
	Supportive environment (EPI5)	
	Staff/resident integration (PI5)	
	Staff/resident integration (FG3)	
	Autonomy of actions (EPI7)	

Enabling

Participants clearly identified that an environment should be supportive of the residents' needs, in regard to autonomy and independence, relationships and comfort:

> *"In a positive environment, people can make themselves a drink, there is clutter and junk around*
>
> *that people can interact with without needing staff to engage with all the time. There are sofas and*

comfortable chairs that facilitate cuddling up with others or relaxing. Soft furnishings that allow people to connect and be connected with. There is also space between where people sit to allow people to walk freely by each other" (PI1)

"The environment is physically not dirty but not immaculate either" (PI1)

"the environment is practical for the needs of the residents but not 'nursey' Not plastic chairs, homely furniture which is mix and match" (PI1)

"The layout of the environment is really supportive of this (residents interacting with others), no chairs lined up round the walls, chairs in clusters which facilitate interactions together" (PI1)

The capacity of the care home environment to enable residents to achieve independent action and independent activity is also identified as important:

"I think the sort of structure where people can easily wander, where they can easily go from point to point, where it isn't a difficulty to wander" (FG1)

"Is it airy? Is it bright? Have they got contact with the outside world?" (FG2)

"It's not just about being able to see the outside world, it's about being able to access it" (FG2)

"I think that a positive environment would be where they had taken thought and time to enable residents, with the signage, not overly confusing for people but enough there to guide people" (PI4)

However participants also identified that the environment should be protective of people who are vulnerable:

"We put sensors on his door, staff were alerted if he moved, and also on the door of the vulnerable person. That was protective" (FG2)

Personalised

The importance of individualised environments was also stressed:

"Not everything the same, but allowing for individuality and facilitating of a home environment" (EPI1)

"More individualised and person stuff is seen lying around, e.g. handbags" (EPI1)

Stimulating

Finally, participants also indicated that the opportunities for meaningful activity would be in evidence:

"A good sign is where people seem to have possessions, it's sad that we have grasped on rummage bags and clutter but that's what we mean, things that people can touch and move that gives them a sense of purpose" (FG2)

"they have something meaningful to do, someone might be laying the table but they're not just 'I've got a beach ball here, let's play catch', but something that is worthwhile and that the resident is thanked for doing" (PI4)

Issues of observation

At the end of the interviews and focus groups, the majority of participants contributed their views on factors that they believed would need to be considered in regard to the process of observation. These are summarised in **Table 8.** These factors were important in our decisions around the process for conducting the observations in care homes. These issues were also discussed with the steering group for the research.

Table 8: Issues raised about the process of Observation

The person with dementia	Staff	Time & place of observation	Issues arising from observation
Safeguard emotional safety of participants priority (EPI3)	Staff will be very anxious (EPI2)	Abusive practice likely in private (EP14)	Triangulation with care plans, records etc (EPI7)
Signs will be apparent in public areas (EPI3)	Ask staff to explain their actions (EPI2)	General observation misses end of life residents (FG2)	Need to look at documentation (EPI6)
Confidentiality (EPI7)	Team must communicate with home staff (EPI2)	Observation in public areas, including hallways and other areas (PI5)	Need to provide advice and support to staff and residents (EPI2)
Mindful of Hawthorne effect (EPI2)	Give immediate feedback (EPI1)	Need to observe personal care (EPI6)	Ensure support structures in place (EPI3)
Personal observation needs rigid protocols (EPI4)	Staff likely to modify their behaviour under observation (FG1)	Observe personal care indirectly by shadowing staff (EPI6)	Need to triangulate data, include family, residents voices etc (FG3)
Highest sensitivity needed in personal observation (FG1)	Home will change practice under observation (FG3)	Personal observation needed (EP14)	Get to know culture of care first (PI1)
Clear protocol needed - when to intervene (PI4)	Sensitivity to needs of carers (PI3)	General observation - potentially misses context (FG2)	Need to be aware of safeguarding guidelines (PI2)
Work within Personhood and Identity (PI2)	Doing obs for long enough for staff to get used to you (PI5)	Personal observation - too invasive (PI4)	Impact of culture of management on observation (PI3)
	Support for carers re outcomes of observation (PI3)	Observation at mealtimes (PI1)	Setting the obs process up as a helpful resource (PI5)
		Observing personal space too invasive (PI2)	Who determines safeguarding issues from poor practice? (EPI7)

General observation/Personal observation

The most prominent theme was whether personal care/private space should be observed. A number of contributors recognised the significance of observing personal care/private spaces:

> *"Entering people's private care, this does need to be observed, lack of dignity and respect is an issue in intimate care, and can be difficult to do observations but do need to find a way of doing this"*
> *(EPI6)*

"Would suggest private place observation – but with consent protocols in place followed – much of abusive practice is likely to occur in less public places" (EPI4)

However, opinion was divided as to whether such observation could be ethically sound:

"I think that's too invasive personally, that's my personal opinion" (PI4)

"I think private space is private space... if it was me being observed in my personal space I wouldn't agree with it" (PI2)

Furthermore others highlighted that relevant information could be obtained by observing at key times and areas during the day:

"I think the communal stuff, the lounge the dining room, sometimes seating yourself in a corridor and seeing what goes past is useful because I think people forget you are there" (PI5)

"I think key times of the day, I think first this in the morning, maybe 6 in the morning, breakfast time, meal times tea times, in the lounge. Also in the twilight times as well, what are people doing from that time between the last meal of the day" (PI5)

Hawthorne effect

Several contributors identified that all staff were likely to alter their behaviour under observation. Two motivating factors were identified as being i) the desire to conceal 'true' practice ii) staff anxiety at being observed.

i) The desire to conceal true practice

Here it was suggested that observation should be particularly thorough and perceptive, for example, by including analysis of documentation for evidence of normative practice. (EPI6)

ii) Staff anxiety at being observed

Contributors affirmed the importance of communication with staff. Researchers should explain their motives and reassure that individuals are not under investigation. (PI3)

Triangulate observational data

A number of contributors suggested that several sources of data would be required in order to provide context for observational data. Examples of other data sources included conversations with staff/residents, care plans, incident records, and staff training records. (EPI7/EPI6/PI5)

Protocol for intervention

The importance of a protocol for intervention was identified by several contributors; such a protocol would reference when and how to intervene should negative care become apparent. (EPI4/PI2/PI4)

> *"The other thing we have found difficult is balancing, trying to get enough information for our observations, with balancing the distress someone is going through" (PI4)*

Support system for participants

Several contributors suggested that there should be a framework of support in place for those involved in the study.

> *"Ensuring people know about helplines and sources of support, other than safeguarding. Provide information leaflets and sources of support" (EPI3)*

Conclusions

Both the themes from the literature and the themes arising out of the focus groups and interviews were remarkably congruent in guiding us in the key issues that the observational tool needed to encompass. Structuring the interviews and focus groups around the themes of Person, Interaction and Environment worked well and all areas yielded lots of discussion. Specifically, those factors that could be considered as indicative of abuse, neglect and loss of dignity (or would be protective of such occurrences) are related here. There was much congruence between the different groups in the factors they would look for as being indicative or protective. These are grouped together under different headings in **Table 9**.

With regard to the person's own overt distress behaviours, anxiety and withdrawal were common themes in both the literature and the focus groups and interviews. The term agitation was used more frequently in respect of discussing negative signs for people with advanced dementia.

With regard to interactions, focus group and interview participants emphasised issues around depersonalised, task focussed care as being a negative indicator and staff knowing and treating people as individuals being a protective factor. These were not mentioned in the literature so much. This may be a particular feature in caring for people with advanced dementia. Getting to know the person with dementia, their life-story and identity is something that is seen as particularly important in positive dementia care and is something that is difficult to achieve (Moos & Bjorn, 2006). The literature mentioned residents not interacting with each other as a negative sign. This was not mentioned in the focus groups or interviews.

This may be because participants were asked to focus on people with advanced dementia who find interaction a major challenge if not well supported by a care giver.

With regard to the general environment, again there was much agreement between the literature and our focus groups interview participants. Having opportunities within the environment for social interaction and freedom of movement were frequently mentioned. The literature emphasised the need for more privacy. This was not raised in the focus groups or interviews.

Table 9: Summary of Negative Indicators & Protective Factors

PERSON			
Literature on Observable signs		**Focus groups and interviews**	
Negative	**Protective**	**Negative**	**Protective**
High levels of emotional distress or aggression	Amount of positive social behaviours	Overt distress behaviours	People free to be themselves
Wary facial expression	Relaxed facial expression	Agitation & anxiety	Relaxed
Withdrawn/disengaged, depressed behaviours	Responsiveness to care recipient to interactions from caregiver	Withdrawn & disengaged	Happy to be engaged and out-going
Poor physical appearance		Unkempt & dirty	Well cared for appearance
Poor dietary and fluid intake over the day		Poor physical state, bruising	
INTERACTIONS			
Literature on Observable signs		**Focus groups and interviews**	
Negative	**Protective**	**Negative**	**Protective**
Few interactions		Resident Ignored	Residents included
Poor quality interactions e.g. aggressive negative	Good quality interactions e.g. affection, fun	Overtly disrespectful	Warm and nurturing
		Depersonalising, all the same	Staff know persons individual Identity
Few interactions between people in the care environment			
High amount of instructional behaviour		Control by staff Power imbalance	Supportive and enabling
ENVIRONMENT			
Literature on Observable signs		**Focus groups and interviews**	
Negative	**Protective**	**Negative**	**Protective**
	Opportunities for and engagement with social activities	Impersonal	Personalised to the individual residents
	Opportunities for engagement in activities of daily life	Barren & boring environment	Stimulating
Restraints to prevent movement		Restrictive and restraining	Enabling, easy to get around
Privacy not respected			
		Uncared for, poor quality	

What we need to observe in the tool

The use and misuse of power was recognised as a core concept to inform the development of the tool and the researchers' attention during observation. This necessitated a focus upon the extent to which residents

were able to exert control within their daily life, or were subjected to the control of others in a manner which diminished their level of personal control.

The indicators highlighted included the need to observe for levels of withdrawal or distress, particularly where this was unattended for significant periods of time. The opposite corollary of this was where residents experienced high levels of engagement and personal identity was reinforced. Furthermore, the development of the tool needed to attend to the nature of interactions experienced by residents, including the purpose and manner of these interactions and the responses elicited from residents.

In addition the tool needed to take into account the environment within which the person exists, and the extent to which this environment detracted from or enhanced the opportunities for well-being of residents. This included observation of levels of appropriate stimulation, attention to privacy and dignity needs, needs for meaningful activity and occupation, and needs for freedom of action and expression.

The process of observation

Additionally participants highlighted factors that would need to be taken into account in the design and delivery of the observational process. Such factors included the need to carefully consider how to introduce and gain staff co-operation in carrying out the observation, where and when to observe, who to observe and when it was appropriate to intervene. This needed to sit within a framework that was respectful and supportive to persons with advanced dementia. The issues set out in **Table 8** were particularly helpful in writing the PIECE-dem manual sections on the process of the observation.

Part 3: Care Home Pilots

Introduction

Following on from the literature review and the immersion in the focus group and interview material, the next stage was to develop a pilot tool based upon this and use a series of in vivo trials to arrive at a final tool that could be used in practice. Based upon previous work in developing the SOFI tool (CSCI, 2008) it was estimated that trialling the process in 15-20 care homes would achieve this. The trials were designed to:

- Clarify what we would observe and how it would be recorded

- Help with resolution of any data collection problems

- Modify the process to make it fit for practice

- Allow some initial reliability and validity testing

Method

The care home settings

They were accessed by open invitation on our web-sites and our current contacts including our student body, safeguarding leads, CQC and the provider network. It was intended that the care homes selected would include as far as possible a range of providers (large corporate providers, single ownership, social services, charitable), sizes of establishment, resident characteristic (ethnicity, gender, age, dependence levels) and quality (poorer performing homes to good quality homes) to ensure a representative sample.

Selection of individual study participants

Potential participants for the research were identified initially by the care home staff in conjunction with the research team. Inclusion criteria for participants included longstanding cognitive disabilities either caused by a dementia disorder or stroke. The research team then chose a convenience sample from this list that gives representation of different people with severe dementia alongside other variables such as a range of mobility, physical health, abilities, ethnicity, gender and which in particular included those who most at risk of abuse.

Exclusion criteria included those without significant cognitive problems, those with a history of paranoia, residents who were newly admitted or whose mental and physical health was particularly unstable.

Procedures

Care homes

Each care home that has expressed an interest in being a study site was sent an information leaflet detailing what the study is about and what involvement will entail for them. If they wished to offer the research team the opportunity of involving their care home as a pilot study site the manager and proprietor (where these are different) were asked to sign and return an expression of interest form giving broad details about the home (e.g. location, size, ownership) and the residents (ethnicity, age, dependency levels) This form was used to assist the research team in deciding on suitable pilot sites that provide a range of care homes and residents to use the pilot tool with.

The research team met with the manager of the care home to discuss the research in more detail. The homes could withdraw their agreement to participate at this stage. If the homes were willing to participate, the research team discussed with the home manager the inclusion and exclusion criteria and obtained a list of potential participants to observe.

Consent procedures

Members of the research team visited each care home on a number of occasions. Following the initial agreement from the management, the research team visited to meet the staff and residents at the home, and to brief them about the research process. They sought written consent to participate in the study from the staff and written or verbal consent from the research participants with dementia or their consultee. It was expected that many participants would not be able to provide informed consent. Information was sent out to relatives of potential participants to inform them about the research and to ask them to indicate if they know any reasons why it might not be appropriate to approach their relative to seek their consent to participate.

The consent procedure in this research was seen as a process rather than a one-off event, with individuals being given information about the study on a repeated basis, and a sequence of opportunities being provided to withdraw if this is their wish. Where a potential participant had communication disabilities or impaired ability to give fully informed consent, the researcher was accompanied by a relative or consultee in seeking their consent. This ensured that their best interests are represented in any decision made. At a time when the participant is most likely to be able to concentrate, the researcher showed the participant information leaflet to the person, and asked for their permission to spend some time talking about the study. If this is granted, after a discussion based on looking at the leaflet and in a way that is appropriate to the person and their communication abilities, the person will be asked if they would like to take part.

If the researcher considers that the person is not able to understand sufficiently to give meaningful consent, but is not expressing unwillingness or anxiety about the idea of participating, then the advice of the consultee was sought. If they agree that the person is not able to give informed consent but does not seem distressed by the presence of the researcher, then the consultee and the researcher signed a form to this effect. If the potential study participant appeared distressed by the presence of the researcher then they were not be included in the study.

The researcher also gathered some demographic information about the research participants including gender, age and diagnosis. This included information provided by the key worker and a structured interview if possible. The amount of pre-information collected about participating residents increased over successive trials as it became apparent that more contextualising information about residents was necessary to make sense of the observations.

Observation procedure

The observation procedure developed over successive trials as this was the primary aim of the research. There were certain protocols that were adhered to through-out however. During the observation period within the care home the ethical conduct of the researchers and reporting procedures of untoward or abusive care practices used in Dementia Care Mapping (Brooker and Surr 2005) were followed. These included:

- Unobtrusive observation;
- Responding directly to questions from staff, visitors and residents/patient;
- Intervening if required if a resident/patient is at risk of harm;
- Reporting abuse, neglect or other untoward practices via pre-established channels, agreed during the consent phase of the study.

Two researchers were present during all observation times, although they would usually be observing different residents in different parts of the home. Verbal consent was sought each time from the participants with dementia prior to any period of observation. The process of consent was on-going. Each time an observation for the research is undertaken, the researcher reminded the person that this is work for the project, and check out that they are still happy to be included. The researchers assessed continually during observation that being observed was not causing distress to the participant. If they felt that observing a participant was causing them distress they stopped observing them immediately. If their presence in the care facility appeared to be causing a participant or any other person with dementia

distress, the observations were stopped altogether in that area. The assessment of consent was therefore an ongoing process. The researchers present ensured that appropriate measures were employed to alleviate any distress in participants if observations were stopped.

On the occasions when research observations were taking place in the homes notices were placed on the walls in prominent positions to remind the participants with dementia, visitors and staff that this is taking place. They advised people with any questions to approach the researchers or the homes manager or staff.

Neither the research participants with dementia, nor the staff working at the homes were expected to do anything different from their normal daily routine.

Feedback of observations

The researcher(s) held at least one feedback session with the staff and other appropriate stakeholders from the home. This focussed on what the observations have revealed. Feedback was sought from staff on the validity of these observations and any issues associated with the process of the observations.

Measures

A range of measures were used at the commencement of the pilot process in care homes in order to gain a description of residents being observed and to have some standardised measures against which to validate the new tool. QOL-AD (Logsdon et al. 2002) is a 13-item dementia specific quality of life measure that has a proxy version that can be filled in by the participants' key worker. A high score indicates a better perceived quality of life. The maximum score for the QOL-AD questionnaire is 52 and the minimum score is 13. Scores were similar across all schemes and across conditions for both the staff completed questionnaires and the resident completed ones.

The BARTHEL (Mahoney & Barthel 1965) is a standardised measure of dependency for basic skills such as using the toilet and mobility. A high score means that the person is independent in these areas. The highest score denoting complete independence is 100. The Clinical Dementia Rating Scale (Morris, 1993) was used to identify the severity of dementia experienced by residents. This is a 6-item scale that is completed by the participant's key worker.

The Care Dependency Scale was used as a measure of dependency in 14 of the residents selected for observation (Dijkastra et al, 2000). A higher score indicates a lower degree of dependency (max score = 80). The scale was introduced midway during the piloting phase of the observation because of the difficulties staff had in being able to accurately ascertain quality of life in residents with high levels of dependency and communication difficulties.

Analysis

It was intended that a quantitative analysis would be undertaken on the spread of scores between and within the care homes in order to establish initial criterion validity and initial inter-rater reliability and test-re-test reliability of the scoring systems. Given the lower numbers of care homes participating, quantitative analysis was limited.

Results

Recruitment of Care Homes

By far the biggest challenge in this programme was the low number of care homes participating. The reason for this was lower take-up was a combination of:

- A wish not to be associated with a programme investigating risk-factors for abuse and neglect. This often followed an initial interest and visit on behalf of the research team;
- In order to gain the confidence of the homes that did participate, the research team were spending on average twice as long as we had initially planned for.

Thus in the time scales available we managed to undertake trials in 7 homes with 11 periods of two-day observations being completed in all. The characteristics of the care homes taking part are summarised in **Table 10.**

Table 10: Care home pilot sites

Sample Characteristics (Care Homes)										
Care Setting	Nursing Home	Residential Home	Ownership	For Profit	Size	Dementia Specific	Urban	Rural	Rating	Inter-rater Reliability
ADS01		Yes	Single Owner	yes	24 beds	No	Yes		Good	
ADS02	Yes		Chain	yes	102 beds	No		Yes	Good	Yes
ADS03	Yes		Single Owner	yes	24 beds	No		Yes	Excellent	Yes
ADS04		Yes	Chain	yes	67 beds	No	Yes		Good	
ADS05	Yes		Chain	yes	50 beds	No	Yes		Good	
ADS06		Yes	Small Chain	yes	65 beds	No		Yes	Excellent	Yes
ADS07	Yes		Chain	yes	97 beds	No		Yes	Good	

The sample had a good mix of nursing and residential settings. Although all the homes were owned by private "for profit providers" there was a mix of single ownership, smaller chains and national chains. None were just registered for dementia. The range of size was wide and fairly representative of the national scene. The CQC ratings were all Good or Excellent. We were unable to attract any poorly performing homes to be pilot sites, although two of the homes had recently been upgraded from poor or adequate.

In-depth observations were usually completed on four residents per home. This equated to 28 individuals whose demographic data is shown in **Table 11** below. The participants were representative of a typical care home population. Of the 28 residents, four had had falls in the past week.

Table 11: Participant characteristics

Gender	Age	Time living at the care home	Diagnosis
20 female	**Mean = 85 years**	**Mean 3 years**	**Dementia = 11**
8 male	**Range 66-102 years**	**Range 2 months – 8 years**	**Alzheimer's Disease = 10**
	Standard deviation = 24. 037	**Standard deviation = 31.76 months**	**Vascular Dementia = 5**
			Other = 2

As indicated earlier, a range of measures were completed for each of the residents included within the study. Although initially there were two reasons for using these measures, to provide a description of participants and to achieve standardised measures against which to validate the process developed, in practice the small number of participating homes made the second purpose unachievable. Thus the scores on each of the measures provide descriptive information about the residents included in the study. This is presented in table 12. Recruitment of participants involved selection of those that had high levels of dependency, which was reflected in the scores achieved within the different measures used.

Table 12: Standardised Questionnaire results

	Qol-AD	Barthel	CDR	CDS
N	**27**	**28**	**27**	**14**
Mean	**25.296**	**26.964**	**2.592**	**31.57**
Range	**15-22**	**0-95 mode = 0**	**1-3 mode = 3**	**16-51**
Standard deviation	**4.589**	**28.782**	**0.693**	**13.776**

The standardised questionnaires that were completed suggest that staff generally rated the participants' quality of life as poor; that they were highly dependent in terms of requiring support and that they had a significant degree of dementia. Thus these residents required a high level of intervention from staff within the home in order that their needs were met. These results, coupled with the pre-assessment information were used to ensure that participants selected were appropriate for inclusion in the study?

The progress of development – key decision points

Following each care home trial the research team met to review the experience gained, critically consider the observations made, and reflect upon the process and structural aspects of the design of the process. This was a highly iterative process, reviewing researcher experience and feedback from the care home sites. The key decisions are shown in **Figure 1**.

Consideration was also given to the outcomes of the focus groups and interviews as well as our knowledge of the literature and existing theoretical standpoints and research evidence. For example after pilot 1, it was clear that drawing conclusions from our observation of people who are very advanced in their experience of dementia was challenged by our knowledge of the person and the sometime minute actions that might indicate an expression of need. It was believed that our observations needed to address the whole person, and that this was particularly relevant to people who are bed or chair bound, where the meeting of their physical needs is particularly important and often formed the frame within which other needs were or were not met, such as touch, affection and communication.

In this context, Maslow's Hierarchy of Need (1970) was considered as the theoretical frame with the potential to inform the observational process. Researchers revisited the codes identified from the interviews and focus groups, and the data achieved from the first observation and explored aligning these with the needs identified by Maslow (1970). Our thoughts subsequently informed the following observation, where it became clear that there were many challenges emerging in trying to apply this frame, in particular that there was a large amount of overlap between the different needs, thus rendering it difficult to make decisions about which category to assign a particular action to.

Therefore following pilot 2, consideration was given to using Kitwood's (1997) 6 main psychological needs with the addition of a category of physical need, combined with indicators of the need being present and actions to address the need. As can be seen from this discussion; this was a highly iterative process, reviewing researcher experience; relevant literature and theoretical frameworks; analysis of focus groups and interviews and finally feedback from the care home sites.

Figure 1: to show flow of key decision points in the development of the observational tool

Pre pilot phase
- Summarised literature, focus groups and interviews
- Initial process development, focus on feelings of person with dementia, their actions and their experience of others, rating from impoverished through neutral to enriched, with qualitative notes to illustrate observations incorporating impact of environment, nature and experience of interactions and evidence of expression of need
- Focus group to explore face validity of proposed process and structure to observation
- Further amendments made to process and structure

Recruitment of care homes
- Recruitment and consent processes commenced
- Timetable set for data collection and iterative development of observational process

Pilot 1
- Process piloted June 2010, feedback obtained from manager and staff
- Researcher reflections and feedback
- Meeting all researchers and steering group amendments made to process and structure of observation, highlighted difficulty of determining needs of residents with advanced experience of dementia
- Consideration of theoretical frame to inform observations

Pilot 2
- Process piloted in second home June 2010, focus on coding and process of observation, feedback and reflections gained from researchers and home staff
- Researchers meeting, iterative exploration of all sources of data and reflections from observations. Process amendments
- Revisiting focus group/interview data to illustrate evidence of expression of need

Pilot 3
- Focus of observation coding of doing and engagement for 10 minutes with qualitative notes.
- Summary at end of observation on extent to which core needs are met
- Third observation early July 2010
- Changes made following observation to structure of observation, addition of recording engagement with objects, observation for 12 minutes followed by summarising of needs

Pilot 4

- Mid July 2010
- Observation of interaction with other, engagement with objects or engagement with world around them
- Summary after 12 minutes of extent to which needs were met in relation to attachment, comfort, identity, occupation, inclusion and physical needs
- Researcher reflections concern with discriminating extent to which needs met

Major review

- Further consideration of framework of observation and theoretical underpinnings, consideration of concepts of power, comfort, occupation, safety and identity,
- Revisiting of focus group/interview data to inform the identification of need
- redevelopment of raw data sheet, exploration of indicators of need

Pilot 5

- August 2010
- Researcher reflection, need for redevelopment of frame of observation, distinguish between interaction, engagement and impact of immediate psycho-social and physical environment
- Recognition of the impact of observation upon the observer
- Need to capture complexity of data more frequently throughout observation

Pilot 6

- Researcher meeting. redesign of observation frame, explicit recording of immediate environment
- 2-hourly summary developed to record needs being expressed/observed, interaction occuring and environment
- Pre-assessment summary developed to enhance observer knowledge of resident during observation, questions focused upon person's physical, psycho-social and spiritual needs, their history and the nature of their difficulties including communication
- Sixth Observation completed

Pilot 7 & 8

- Forms and process piloted in 2 further care homes, further reflection and discussion
- Further development of 2 hourly summary of observation
- Development of key questions every 2 hours to inform the feedback session. Questions focused upon the person's experience of their world, the level of control they can exert, their psycho-social, spiritual and physical needs, the interactions they experience and whether a connection is made and the extent to which the environment supported the needs of the person with dementia.
- Tool formalised as **PIECE-dem** process Person Interaction Enviroment in Care Expereince

Pilot 9, 10 & 11

- 3 Care Homes revisited with 2 observers
- Observation carried out with PIECE-dem over 4 separate time periods
- Structured observation of 2 residents followed by comparison of data obtained to assess initial inter-rater reliability

PIECE-dem Process

The resulting tool, which we have called PIECE-dem Observational Process has been trialled in a variety of care homes by researchers with varying expertise in observational work. A full manual which details all the conduct and coding decisions is included within this report in Appendix 1. A summary is provided below.

PIECE-dem illuminates the experience of those people who are most vulnerable in long term care settings to experiencing a poor quality of life. PIECE-dem is an acronym for:

Person

Interaction

Environment

Care **E**xperience

in Dementia

During a PIECE-dem, 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. They include those who: are least able to communicate; may be withdrawn; may be at end of life; have bruising or other physical warning signs; are viewed to have high levels of challenging behaviour/un-aesthetic behaviours/sexual behaviours; are very mobile or agitated; have sight and/or hearing loss. The reason for focusing on this at risk group are that they have high levels of need for staff interventions which support their well-being and that if the care they receive is supportive we can be fairly reassured that the care received by residents with lower levels of need receive will also be supportive.

In order that we can be sure of making observations on enough residents with a variety of needs we may collect initial information on 6-8 residents. This means that if any are unhappy with us spending time with them then we have some lee-way in working with those who are not distressed by our presence.

Prior to the observations, the researcher speaks with the key worker to complete the pre-observation summary which covers what is known about physical, psychological, social, spiritual, and communication needs and the participants history, diagnosis and medication – see **Figure 2**.

Following this, the researcher meets all the potential participants and makes a final decision on who will participate. This decision is based on achieving a mix of different needs and excluding anyone who appears uncomfortable with the researchers' presence. The key-worker and/or relative/significant other and

researcher explore the residents' ability to consent and approach the resident to explain the research. Consultee consent is completed if the person is unable to consent, but shows no signs of distress at being in the presence of the researcher. Further attempts are made if appropriate to explain the researcher's presence during the period of observation. Every effort is made to ensure that the resident is comfortable with the researcher's presence during observation. If this cannot be achieved then the observations are discontinued.

Figure 2 PIECE-dem Pre-Observation Summary

Daily life: What is this person able to do for themselves? What does this person need help and assistance with? What does this person enjoy doing? Who this person like spending time with? Does this person have spiritual beliefs that are known about?
Understanding the person's needs: How do you know when this person is happy and content? How do you know when this person is unhappy or uncomfortable with what is happening to them? How do you know if this person is experiencing pain?
Health: Does this person have a diagnosis of dementia? Do you know what type and when this was made? Does this person have any physical illnesses or problems that affect their daily life? What medication is this person taking currently?
Life before coming to the home: What roles have been important to this person during their life? What influence do these roles and their history have on their behaviour now?

One researcher can work with two participants during the same time period, spending time with each participant in 15 minute blocks over a two-day period, covering a typical waking day. Our decision to cover a typical 'waking day' arose from the recognition that although there would be value in observing people at night, it was felt to be too invasive to be present during this time under the auspices of the present study. If night-time issues were the focus of study or enquiry there would be no reason why the PIECE-dem could not be utilised at night-time.

The typical waking day involves time in the evening of the first day, during which in the homes we observed, a handover to night staff occurred and we were able to observe the experience of care with this change in staff. We achieve this over two days in order to observe how different staff impact upon the experience for each participant. Additionally, our experience of observation demonstrated unsurprisingly that residents could vary quite considerably in their well being from day to day and hour to hour, and that it was therefore advantageous to the results of the observation process to capture different days as well as time periods. We observe 1pm- 9pm on day one and 8am till 1pm on day two. The selection of the time periods reflected that on the first day, we wished to capture the handover to night staff and key points during which needs are met. On the second day, commencing at 8am reflected that many of the participants we observed were not out of their rooms until this time, reflecting natural waking and personal care needs. As we had agreed not to observe personal care, it was not appropriate to be present during this time, although some flexibility needs to exist in regard to time of commencement on the second day, and indeed ending on the first day to fit with the residents normal routine. The research team's experience with Dementia Care Mapping also informed this decision, recognising that as staff become familiar with researchers, it is possible that the Hawthorne effect diminishes (Martin & Younger, 2001). A typical timetable of observations for one researcher is shown in **Figure 3.**

Using 1-minute time frames the researcher makes observations of the participants' experiences of the world around them, including recording levels of engagement, the interactions that occur with the participant and their immediate environment. For each minute, the researcher records:

- If the person appears engaged with the world around them or disengaged;
- If an interaction occurs;
- Qualitative notes describing the person's apparent experience of the world around them, what their needs might be, the nature, intention, and experience of interactions and the extent to which apparent needs are met.

Additionally the researcher will take qualitative notes describing the immediate environment within which the resident exists, which includes the extent to which the environment supports the physical, psycho-social and spiritual well-being of the resident. A data sheet is completed for each participant. An example is contained in **Figure 4.**

Observations are summarised every 2-3 hours on each resident. An example of a summary sheet is contained in **Figure 5.**

The Summary for observation involves:

- Actions (and their possible intention) that may be observed/expressed by the **Person** with dementia, this includes their facial expression, body posture, bodily movements, attempts at communication, vocalisations;
- Direct actions of others as they relate to the person with dementia. This includes the nature of the **Interaction** and how this appeared to be experienced by the person with dementia. Recording includes the posture, tone, content, apparent intent, use of touch occurring in the interaction;
- The immediate physical and psycho-social **Environment** surrounding the person with dementia.

Prior to and during observation, the immediate physical and psycho-social **Environment** surrounding the person with dementia in relation to their sensory experience, the management of the environment and the physical environment and the extent to which it appears to support the person's needs is summarised. This includes what the resident can hear, see, smell and experience from where they are.

Observations occur in public areas and in hallways. Because PIECE-dem tracks an individual's experience of care, some observations are undertaken in or immediately outside the person's room. This is particularly the case if the resident is spending long periods in bed or is bed-bound. Intimate care activities would not be 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 will include times of high demand for staff interventions, including mealtimes 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.

Following the period of observation, the summary is fed back and discussed with the key-worker and manager. During the summary we may highlight different situations we have seen where the participant is in states of relative well- and ill- being because of interaction or environment factors. For example, a

resident may look very relaxed when she had a blanket in her chair whereas when she didn't have a blanket her posture became tense – different environment factor coinciding with different body posture. Likewise, we might have observed a resident being fed and struggling to swallow whilst at another meal the member of staff used a different approach and the participant appeared much more relaxed – different interaction factor.

The entire process is summarised in **Figure 6.**

Figure 3: Typical Timetable of Observations in PIECE-dem: 1 researcher: 2 residents

Day 1	1pm	15	30	45	2pm	15	30	45	3pm	15	30	45	4pm	15	30	45	5pm	15	30	45
Resident 1	█		█		█		█		█				█		█		█		█	
Resident 2		█		█		█		█		█				█		█		█		█
Break											Early Afternoon									

Day 1	6pm	15	30	45	7pm	15	30	45	8pm	15	30	45
Resident 1			█		█		█		█			
Resident 2				█		█		█		█		
Break	Late Afternoon										Evening	

Day 2	8am	15	30	45	9am	15	30	45	10 am	15	30	45	11 Am	15	30	45	12 pm	15	30	45	1pm	15
Resident 1	█		█		█		█				█		█		█		█		█			
Resident 2		█		█		█		█				█		█		█		█		█		
Break									Morning												Middle of day	

Figure 4: Example of completed data sheet

PIECE-dem Raw Data Sheet Participant no. Ellen   **Time Start: 10.53   Time Finish: 11.08**

Time Frame Notes													

Table 1	1	2	3	4	5	6	7	8	9	10	11	12	Total
Interaction		x	x						x				3
Engaged													
Disengaged	x			x	x	x	X	x		x	X	X	9

1	Ellen continues to sit in the dining room, eyes open but staring into space.
2 3	Carer moved her chair and asked Ellen to stand up, she didn't warn her that this was going to happen, Ellen appeared shocked. Carer took her arm and walked her towards the door, Ellen was walking at a pace that appeared faster than she could manage, and the carer was walking in front of her and didn't appear to notice till the last minute that Ellen was walking towards a door frame. Ellen appeared upset and alarmed. Carer sat Ellen down in a chair in the hallway.
4	Ellen tried to get up; Carer moved her chair without telling her this was going to happen. She remained in the chair, looked down towards the floor after the action of the member of staff.
5	Ellen sitting in a chair, facial expression suggests she is distressed or sad, not engaged.
6	As 5
7	As 5
8	As 5
9	Carer interacts with Ellen and asks if she's ok, bends down to her eye level. Asks her what's wrong, Ellen doesn't respond to this, continues to look into space, staff moved away.
10	Sitting in a chair appears withdrawn, looking down towards the floor, eyes half closed, body posture appears quite tense, arms folded.
11	As 10
12	As 10

Immediate Environment
Still in the dining room, in a chair. Radio still on, on heart fm, next to her table. No evidence of social interaction, or engagement with other residents in the room. She is sat in a chair which is not supportive given that she appears sleepy. Has been in the dining room since before 8.30am. Hallway she moved into is dark and has little to offer stimulation; her soft toy is not by her chair as it was yesterday.

Figure 5: Example of a completed 2 hourly Summary

Summary of Observation Block   **Participant Number: 05**

Tick which observation block you are summarising

Early afternoon	Late afternoon	Morning	Middle of day ✓

Record Number of minutes spent in each category					
Interaction	15	Engaged	24	Disengaged	11

Summarise your perception of the person's predominant experience of their world during this time period

John seemed at times to find it difficult to make sense of others intentions and the world around him. He sometimes appears concerned about what is happening, for example he sometimes frowns and pulls at his trousers when an interaction occurs. He sometimes says no to attempts at interaction or intervention, but is not angry with carers when they occur. So is this about his capacity to process information and understand?

To what extent was the resident able to exert control within their world and how was this achieved?

John seemed to have some capacity for taking control, but his difficulties with language seemed to be a source of frustration for him in this regard. He seems to exert control when interactions are attempted by carers, by saying no, or appearing to consciously ignore something someone is saying to him. He pushed his cup away from him when he had finished his tea, despite being prompted to continue to drink. Carers didn't always appear to accept no from him when they wanted to do something for him.

How were the person's physical needs met?

His physical needs for a safe transfer from chair to wheelchair seemed to be met appropriately; he did not appear concerned at all about this process. He was offered a number of drinks during the 45 minutes I was observing him. I did not see evidence of him appearing uncomfortable during the time I observed him and he was encouraged to walk a little way from the chair to the wheelchair.

How were the person's psycho-social and spiritual needs met?

Johns psycho-social needs in regard to relationships appeared to be met while I was there, as his wife came to visit and had lunch with him. He appeared to recognize her and was more alert and responsive when she arrived. However his need for enriching activities did not appear to be met, he spent a fair proportion of time appearing to seek interaction without receiving it, looking around and trying to engage eye contact with others with little success.

When do interactions occur, who is the interaction with, what appears to be the purpose of these interactions and what impact do they have upon the person with dementia? Was knowledge of the person used in the interaction?

Interactions with Carers focused mainly on tasks to be completed. These were explained to him in some detail, but he often said no, which made me wonder if he understood what was being said to him. On one occasion, a carer made a considerable effort to talk with him and his wife, and he smiled and laughed with her. Additionally he seemed much more animated with his wife, laughing and talking with her. However, there were occasions when carers talked over him, particularly when serving out dinner. He was not offered choice about what he wanted for dinner, and his wife indicated that he didn't like what he had been given. The carer was happy to change the meal offered at that point.

Was an empathic connection made during interactions between staff and resident? (describe how this was achieved and if not, why it appeared not to occur)

Interactions with carers seemed to rarely achieve a real connection with him. Where they were successful, the staff member had spent time bending down and attracting his attention for quite some time before explaining what she wanted to do. His wife did seem to make a connection with him, particularly when she showed him photographs of his grandchildren and she also took some time with him, patiently explaining what the event was that had happened.

What facilities were present within the environment to support the person's identity, occupation and inclusion? Were these facilities made use of in interactions with the person?

Little evidence of facilities that could support his identity and occupation needs. He did look at the newspaper at one stage, but seemed to struggle with this, I felt that this maybe too complex for him. While carers used his name, and talked with him, they didn't appear to know much about him. His wife showed him photographs and this seemed to be particularly enjoyable for him. She talked about family and he responded to this with gestures and nods and pointing at different people and their pet dog.

What emotions did you experience during this period of observation and why?

I felt quite frustrated because it seemed as though he could enjoy some activities and engagement but that he needed extra help with communication. He seemed to feel frustrated at times, (was I mirroring this?) wanting to engage and not being given the opportunity and I am concerned that there is a real risk of him becoming withdrawn if his attempts at communication aren't responded to.

How do you think staff experience this person?

It seems as though he came with a history of being challenging, from the home he was in previously and I wonder if carers find him a bit difficult to communicate with/ are worried about doing the wrong thing. Maybe they also are worried because they also know I am watching. A couple of the carers made a particular effort, one of the male carers interacted with him and his wife during dinner and seemed to make a connection, so seem to feel less concerned about interacting with him.

Other comments

How much is known about his life history and his occupation? Is there a way of involving his wife in working with him?

Figure 6: Summary of PIECE-dem Observational Process

Pre-observation checklist completed

Researcher and staff member approx 2 hours	Highlight what is known about residents and assit in the interpretation of observations

Consent and selection of residents to be observed

Researcher and staff member 10 minutes per participant	Final decision select 4 participants

PIECE-dem observations

Continuous observation of participants in 15 minute blocks from 1pm- 8pm on first day and from 8am to 1pm second day	Observe what is happening to each particpant, their engagement , their interactions and environment

Post PIECE-dem

Researcher reflection and debrief prior to feedback	Summarise observations and feedback to key worker and manager for approximately 1-2 hours

Process Issues in Observation

There are a number of structural and process issues which were identified during the focus groups and interviews, and subsequently during piloting of the process. Many of these centred on the use of non-participant observation which clearly has the potential to be intrusive and to cause worry or distress. Researchers were consequently mindful and discussed in some detail the boundaries of practice in this regard. A number of issues are addressed here;

Unobtrusive observations

The importance of being as unobtrusive as possible during observations was apparent from the researchers experience with Dementia Care Mapping. Researchers limited the number of things they carried into the observation. Concerns about positioning were challenging, particularly in the context of smaller lounges or observation of people who chose to walk around during the time they were being observed. In smaller lounges, it was at times difficult to remain unobtrusive, given that many of the chairs were taken by residents and visitors, and there was little space to sit 'out of the way'. During these times, the status of non-participant observer was more difficult to maintain, as interactions were more likely to take place and activities were sometimes occurring. Researchers as a consequence sometimes got involved in activities, for example when a musical activity was occurring, the researcher got involved in singing along with residents. Although this was challenging in terms of recording, it did result in the observer being less obtrusive. Observers also found that residents frequently became more aware of our presence. This was in part because observing for 15 minutes at a time can be quite intense, so it was necessary at times not to look directly at the person all of the time, and to monitor their reactions to your presence so that their privacy and well being needs can be respected and responded to appropriately.

Observation of residents included where appropriate, following them at a discreet distance into the hallways and other areas of the home as well as sitting and dining areas. While there were occasions when others were walking that the observers could remain unobtrusive, at a discreet distance, it was also necessary to assess the environment in which this was taking place. For example one lady being observed walked up and down the corridors near the bedrooms, and only a few other residents were present at this time. Therefore observation was limited to sitting in a chair that was already present in the hallway, and only observing as the resident passed by/ could be seen.

Observations during receipt of personal care

Although some participants in focus groups felt it might be appropriate to observe during personal care, the majority did not and as a consequence of these expressed views and the experience of the research

team, the decision was taken not to do this. During occasions when the person was taken to the toilet or to their bedroom to meet their care needs, observers on occasions followed at a discreet distance and stayed near their bedroom or bathroom. The purpose of this was to observe the person's reactions prior to and after they have received care. This did not involve 'eavesdropping on the interaction occurring in the room, as it was felt that this would be inappropriate, particularly as it was not possible to see the reactions to the interactions occurring, thus any observations made could be entirely misleading.

Observing in bedrooms

Some of the participants observed were bed-bound or chair bound and spent significant periods of time being cared for in their own room. This presented particular challenges for observers, in regard to negotiating how and when it was appropriate to observe a resident in these circumstances. For example one of the participants generally spent at least 2 to 3 hours in bed during the afternoon. The researcher followed at a discreet distance, but observed that it was not possible to see the person without entering the room and sitting in their line of sight. This was deemed to be too invasive, subsequently the researcher sat outside the room, but close by, and was able to observe some of the postural changes and reactions to interaction when these occurred. Subsequent discussions identified that boundaries needed to exist concerning observation in private spaces such as bedrooms, which included that observation in such spaces can only occur if:

- This is not upsetting for the person;
- No personal care is being carried out;
- The person does not have visitors;
- Your observation is not off-putting for a staff member or the participant, for example causing the person to behave differently e.g. putting them off eating.

While researchers asked permission to enter someone's private space, and on occasions did sit in the participant's bedroom, it was recognised that such observations were significantly affected by the changed nature of the relationship with the participant in this context. Researchers were required at times to move towards participant observer, in engaging with/ interacting with the participant. Such a change in the relationship needs to be considered very carefully to respect the person's right to privacy. Additionally, it is possible that this could create a false impression of the relationship for the participant. Thus such occurrences were carefully monitored and discussed, to ensure that the rights of residents were respected.

Feedback from care home staff

The purpose of the researcher's presence in the home was to pilot the observational process and determine whether our observations accurately represented the experience of the residents. During the process of gaining consent from the manager and staff within the home, the purpose of the observation was stressed, and efforts were made to engage staff in a collaborative process in which the researchers highlighted the need for and welcomed feedback during and following observation from staff and other visitors within the home. Researchers made considerable effort to engage with staff prior to and during observation, explaining what they were doing and answering questions. While the position of researchers during observation was generally that of non-participant observer, this did not mean that researchers were unapproachable. Indeed this was a particular concern expressed by one of the care homes, as they had recently been 'audited' using another form of observational process, and had found the approach of the observer to be distant and un-approachable, which resulted in them having a significant degree of reticence about taking part in this study. Researchers greeted staff in both afternoon and morning sessions and explained what they were doing. Interactions occurred with staff, residents and visitors to the care home as appropriate during observation. It was apparent that when researchers were flexible in the extent to which they engaged with residents and staff, such actions resulted in less anxiety among staff about our presence.

At the feedback session, to address some of the concerns about the power relationship, researchers began by asking the staff for their comments on the researchers' presence and their experience of this. Negative as well as positive feedback was encouraged. Following this, the researchers gave tentative feedback about the observations they had gained for each resident, inviting staff to consider how congruent these observations were with their own perception of the residents being observed. Researchers began with feeding back positive observations and moved on to considering challenges as discussions continued. It was emphasised that the researchers do not know the residents, so the staff's perceptions were of considerable importance in supporting the development of the process. Following this discussion, consideration of the key issues and their implications for practice was explored with staff and managers. It was frequently the case that care home staff sought to consider ways in which care could be adjusted to address the needs of residents being observed and on occasions considered the implications of the observation for residents more generally within the care home.

In order for the experience to be productive for care home staff, it would be necessary for the feedback session to be followed up by written information so that staff have time to reflect and consider this in relation to their residents and their practice.

A common concern in observational studies such as this involves the Hawthorne effect. That is, the extent to which the observers' presence influences the behaviour of staff and residents and specifically that the observer's presence results in behaviour change that does not accurately reflect the norm within the observational setting under study (Chiesa & Hobbs, 2008). Feedback regarding the experience of being observed suggested that staff had not found this to be too intrusive, with some commenting that they had forgotten that researchers were present. Nevertheless, in one of the pilot homes, a manager felt that some staff had interacted less with residents due to the presence of the researchers, however this was not reflected in the staffs' comments about their experience of the observation. Nevertheless, the researchers recognise the powerful position they held while present in the home, and in the delivery of feedback to staff, and as such feel that it is likely that staff were affected by their presence, but that the approach taken by the researchers and the length of time present may have mediated this initial discomfort for the majority of staff.

Thus in the majority of the pilot sites, the feedback was well received, with comments from the key workers, staff and managers indicating that observations concerning the experience of the person with dementia were congruent with their own knowledge of residents, and in some cases offered further insights which were welcomed.

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. It is difficult to know whether this reflected a lack of understanding on the part of the staff and/or a desire to avoid being observed. Certainly, on at least one occasion, a researcher witnessed a member of staff making significant efforts to avoid making eye contact with the researcher and being quite abrupt when in the lounge where the researcher was sitting. However, it is also possible that it is due to researchers misjudging the resident experience or the approach they used with staff, or a combination of these reasons. It does however emphasise the importance of creating a positive frame for carrying out the observations. Also, for providing support to staff, as was indicated in the focus groups and interviews and therefore the need to incorporate clear guidelines for observer practice in the introduction and delivery of PIECE-dem. Opportunities for further discussion of the experience of the process with managers and staff, after observation and feedback has been completed including the provision of anonymous feedback sheets may be a way of understanding the extent to which staff are influenced by the process.

The emotional impact of observing

Observing in a care setting can be an intensely emotional experience. Innes & Kelly, (2007) describe the difficult emotions involved in observing poor care practice. It brings observers face to face with shortcomings in a service they may previously have thought was good and may evoke feelings of inadequacy that they have not intervened when practice is poor. During the experience of developing the observation tool as researchers, we found ourselves experiencing a powerful range of emotional responses to the experiences of the people with dementia who we were observing. 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 the observations 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 the observation. These were situations such as: the person remaining in the same position for long periods of time and showing subtle but clear signs of discomfort; clearly struggling to get comfortable in a chair; struggling to get out of a chair; reaching for an object and struggling to succeed; not being enabled to have sufficient fluids; calling out but not being responded to, or experiencing significant emotional pain or withdrawal which appeared to remain un-noticed by carers. Watching and waiting for a carer to respond was emotionally distressing when one could have simply assisted this activity in a moment.

In discussing these experiences during our debriefing meetings we began to question our moral and ethical position as 'non-participant' observers of people with dementia who were not in a position to understand our reasons for being present in their environment, These feelings were due to our realisation that, no matter how covertly we attempted to conduct the observations, almost all became aware at some time that they were being observed. This was demonstrated in their responses, such as: attempting to maintain eye contact; approaching us and attempting to engage; etc. This produced an emotional and moral dilemma for us in attempting to maintain the 'researcher' stance whilst struggling with the emotional and moral imperative to respond to their 'call'. These experiences need to be taken into account when preparing researchers, managers and practitioners in the use of the PIECE-dem tool, and result in a need to engage flexibility in responding to residents, thus moving on a continuum of non-participant to participant observer as the situation demands.

Inter-rater reliability

During the final three trials in the care-homes we were able to gather initial inter-rater reliability data on the data collection. This was established between two researchers observing the same resident. Minutes observed and percentage concordance is shown in **Table 12.**

Table 12 Inter-rater reliability concordance

Resident	Total minutes observed	Percentage concordance	Areas of Divergence
ADS02a	48	100%	None
ADS02d	96	96%	Interpretation of engaged or disengaged
ADS03a	60	83%	Interpretation of movements and significance of these
ADS03b	60	100%	None
ADS03c	36	100%	None
ADS03d	35	77%	Interpretation of engaged or disengaged
ADS06a	67	96%	Interpretation of engaged and disengaged
ADS06c	96	95%	Interpretation of engaged and disengaged

Concordance or agreement on observations was generally high with some occasional discrepancies around the labelling of engagement versus disengagement.

Part 4: Discussion and next steps

This programme of study has developed an observational process that can be used in care homes to elucidate the experience of people with advanced dementia who are usually seen as "hard to reach". Our experience of spending many hours sitting or walking alongside this group of people underlined for us how vulnerable this group are within the care system. These confirmed that some aspects of conceptualising care in institutions as discussed by Goffman (1961) continue to exist many years later, where such practices as 'ordering the disorderly' Oliver (1999) and malignant social psychology (Kitwood, 1997) were part of the fabric of the culture of care.

In our observations we saw little that could be described as deliberately abusive. However, much of what we observed in many care settings was certainly neglectful of people's physical, psychological and spiritual needs. We observed a great deal of lack of stimulation, lack of attention to emotional distress and a lack of awareness of how people were struggling to cope with their physical and social environment. However, through 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 feed-back sessions with staff, we also witnessed an enormous amount of care and concern on their part to provide good quality care. We also witnessed a lack of knowledge from staff about the life histories of the people they were caring for and a lack of knowledge and skills about how to care for people with advanced dementia. In some of our study sites, where staff were very knowledgeable about their residents and where they felt confident in their care practice we observed residents who were more relaxed, who had plenty of interaction and who enjoyed their environment.

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. The patterns of observations in each home tended to be very similar across residents. If we observed a lack of empathic connection with one resident, the chances were that there would be a lack of connection with all the residents we observed in that care

home. If we observed a high degree of lack of engagement in one resident, the chances were that there would be lack of engagement featuring in the PIECE-dem observations for other residents. This resonated with the findings from our earlier work from the thematic inspection of 100 care homes using the SOFI tool to inspect the care of people with dementia (CSCI, 2008) where we found that highly disengaged behaviour tended to cluster in those homes where there was lack of leadership and staff training. Our experience in developing PIECE-dem also underlines the importance of conceptualising the care culture taking into account a structure like the "Senses framework" (Nolan et al, 2001, 2008) that focuses on the interdependence of relationships between residents, staff and families in determining the quality of the care environment.

Our experience in developing PIECE-dem indicates that it provides a process that appears to be sensitive enough to pick up both neglectful and supportive practice that in turn are likely to be related to factors within the care culture that increase or protect them from abusive practice. We need to be mindful of overstating this claim as our limitations on piloting mean that the tool has not yet been thoroughly trialled by observers who have not been steeped in the development process of the tool.

Limitations to the study

On reflection, the literature review undertaken at the commencement of the study could have been more robust. Too little time was allowed within the study plan. We looked at literature specifically utilising observable signs of abuse and neglect in older people, children and learning disabilities but only identified 10 research papers. Including other databases such as CINAHL Embase, Cochrane Database or Google Scholar may have yielded more.

Whether a broader review would have yielded different broad headings to structure the focus groups and the subsequent development of PIECE-dem is difficult to judge in retrospect. However, the headings of *The person being observed; Interactions with others; the General Environment* were quite broad in themselves and the discussions in the focus groups and interviews covered a wide range of topics. Had our limited literature review ommitted a very significant topic then we would expect that this would have been raised by the external steering groups or through our interviews and focus groups.

The major limitation to this study was that we only managed to pilot the tool in seven homes on 11 occasions instead of the 15-20 that we planned at the outset. The reasons for this were complex but mainly centred around the two issues of low recruitment because of concerns on behalf of care homes about being associated with a programme investigating risk-factors for abuse and neglect and what this might lead to. In addition to this, in order to gain the confidence of the homes that did participate; the research team were spending on average twice as long as we had initially planned for.

Recruitment of care homes was a long protracted process. It involved three days absolute minimum to gain consent from managers, staff, residents and relatives and this required two members of staff. Meetings with relatives particularly required the expertise of JLF who drew heavily on her experience as a Mental Health and Admiral Nurse to help work supportively with people's anxieties. Because of the sensitive nature of the observations we decided always to have two researchers on-site doing the pilot observations. We made this decision early on because of the distressing emotional impact that researchers were experiencing during observation periods. Having two researchers present has enabled on-site discussions and changes to the tool in situ and has also meant that the two researchers can provide support to each other when difficult situations are encountered. It has meant that we have not had the capacity, however, to undertake as many pilot evaluations as we had planned.

Because we did not settle on a final pattern for PIECE-dem until the seventh care home, we do not have enough data in a standard format to have undertaken formal validity testing against QOL-AD and the dependency measures. Initial inter-rater reliability appears good between the researchers but we have not had the opportunity to test the tool using novel observers. We also still need to establish test-retest reliability.

Next steps

The work to date on PIECE-dem has achieved a manualised tool that will be used within the will be used in the final PANICOA study (CHOICE: Care Home Organisations Implementing Cultures for Excellence). This study will use comparative case study design, with a series of 12 in-depth case studies of care homes. Case study will provide a method for examining activity in context, using multiple methods and data sources (Stark and Torrance 2005) to

triangulate data and interpretation of experiences of care, care giving, and organisational cultures and practices from key perspectives (Stake 2005). Comparative case study design supports the development of knowledge and theory as in-depth study of each case in a series develops, tests and deepens understanding (Eisenhardt and Graebnor 2007). Within each case study the PIECE-dem observational framework will be used in order to illuminate the experience of those people living in each of the care settings who are among the most vulnerable to experiencing a poor quality of life. The findings from PIECE-dem in each care home will be used to help direct the sampling of participants, issues and observations of the ethnographic data collection. In this way, organisational cultural and practice issues will be examined both from the bottom up, working from the detailed minute by minute experience of care, and from the top down as discussions, fact finding and orientation with managers in the entry stage of the case study begins to indicate particular issues impacting on the care experience in each case study.

PIECE-dem also has the potential to be used as a tool for practice development. Further work will be undertaken to assess its usefulness in this area.

Over the next twelve months it is intended that the following will be achieved:-

- We will develop a short training session that will initially be used to train the other researchers involved in the CHOICE study in the use of PIECE-dem

- Through the CHOICE study, we will gain feedback from researchers using PIECE-dem who have not been involved in its development. This will enable us to make any changes necessary to the manual and the training session in light of feedback gained.

- During the CHOICE study we will gather further data to complete the validity testing that we were unable to do as part of this study.

- As part of the CHOICE study we will undertake further inter-rater reliability testing with researchers who have not been involved in the PIECE-dem development. From the data gathered we will also undertake formal test-retest reliability.

- Once the work on validity and reliability is complete we will prepare a paper for publication in a peer review journal. We will also prepare conference presentations for both academic and practitioner audiences.

- We are preparing a paper for peer review publication on the emotional aspects of undertaking research in dementia care and care homes. Our expereinces within the development of PIECE-dem will feature in this.

- We will promote the use of PIECE-dem as a observational process for other researchers to use in mixed-method or qualitative enquiry.

- We will undertake a further meeting with our steering group to help design a series of reflective questions that would make PIECE-dem useful and usable by care-home staff. At present the reflective summarising questions in Figure 5 have been designed with researchers in mind. These could be modified further to be particularly useful as a practice development reflection tool in care homes.

- The PIECE-dem manual is currently written with a research audience in mind. We will prepare a manual that will be accessible to practitioners and develop training materials and reflection processes around this as more experience is gained.

- We will trial the PIECE-dem as a tool for practice development within our education and training programmes initially at the Association for Dementia Studies at the University of Worcester.

- We will look at ways of assessing the usefulness of different ways of feeding back from PIECE-dem in practice ie what are the most effective ways of feeding back to other members of staff or to care home management.

- Within this current programme and in the literature generally there is an absence of examples of good practice in the care of people living with advanced dementia in care homes. It is our intention to draw together such examples from the current research, from the CHOICE study, from other care home research and from practice. This could form a publication around good practice. It will be of interest to care providers, commissioners and regulators such as the Care Quality Commission.

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Appendices

Appendix 1 – The PIECE-dem Observational Process Manual

The PIECE-dem observational process

Manual version 1

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Association for Dementia Studies

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Acknowledgements

Contents

Introduction

The development of this process was funded by The Department of Health's Policy Research Programme (PRP) and Comic Relief as one of a number of projects making up the PANICOA (Preventing Abuse and Neglect in Institutional Care of Older Adults) research initiative. For further details of this initiative go to www.panicoa.org.uk

This process was developed within the 'How can I tell you what's going on here?' study. The study's aims were to design an observational tool that can identify risk factors for abusive, neglectful or disrespectful care and also identify protective factors associated with supportive, nurturing and respectful care. The observational tool is designed to capture the experiences of people living with dementia in care homes who are not able to tell us directly about their experiences due to the nature and severity of their disabilities. It particularly focuses on those who are most vulnerable, for example because they have little or no verbal communication abilities, they are cared for in bed, are very agitated or judged by care staff as presenting very high levels of 'challenging behaviour' or because they have sight or hearing loss.

The PIECE-dem Process

The following sections detail the process of achieving access and ultimately gaining consent to use the PIECE-dem process, from people living with dementia, their relatives/supporters and staff working within the organisation. This is an integral part of the PIECE-dem process, enabling informed choices to be made and creating opportunities for a collaborative process to begin. This collaboration ultimately results in positive care practice being recognised and valued, and action plans to address areas of development to improve care practice.

Setting up the observational process – letting people know what is going on

It is important that everyone in the care environment is aware of what you are doing when you are conducting PIECE-dem observations, so that all those present during the observation period are able to make a choice about their participation/presence. The purpose of PIECE-dem makes it particularly important that this process is followed rigorously. Staff, residents and relatives are likely to experience significant sensitivities about the process and what it might reveal. Consequently you will need to be open and honest about the boundaries within which you are working, your obligations and the obligations of the organisation you work for in regard to safeguarding of vulnerable adults.

The following sections detail what you need to do to ensure that information about PIECE-dem and your work in the home is made available to everyone who may need it, and that you have achieved consent where this is required. Below you will find four processes described concerning negotiating access and gaining approval to commence consent processes with residents, the one you select will depend on your position in relation to the home you will be doing the observation in. Following this, the next section addresses consent with residents.

Gaining consent as a researcher

Stage 1: Ethical Approval

The first stage of gaining consent within this context involves ensuring that you have achieved appropriate ethical approval from the relevant local ethics committee, before approaching the organisation/care home. Part of the process of achieving ethical approval will involve the development of information sheets for the organisation, for staff, for residents' relatives and for the residents themselves.

Stage 2: Making Contact

Having achieved ethical approval, make formal contact with the Manager/Owner/ Organisation through a covering letter, an information sheet explaining the research study and explore if it is possible to arrange a face-to-face meeting. It is important not to underestimate the time needed to achieve this, and to anticipate the various concerns that they may have about your proposals. Be prepared in a face-to-face meeting or a telephone call, to explain the process in detail and the importance of consent at all levels. Be prepared for the possibility that the organisation may need to go through various procedures before giving agreement to participate.

Stage 3: Informing and Gaining Access

Once approval has been achieved, your next step should be to arrange to meet with the manager and if possible the senior care team. You will need to repeat the process of explaining in detail the research study, the inclusion criteria for residents and the process of consent. Once you have gained consent, your next step will be to work with the manager and staff to identify a date to offer at least one meeting for staff working within the care setting and at least one meeting for relatives of residents within the home. These dates should be planned for at least 2 weeks ahead in order that staff and relatives are able to attend. At this point you will need to provide the following materials for the manager:

1. Copies of your information sheet for staff including the date of the staff meetings and consent forms, and a box in which staff can place their completed consent forms;

2. Copies of your information sheets for relatives of residents, including a covering letter explaining the reasons for this contact, and the date of the meeting. This information sheet should also include offering relatives the opportunity to be involved in the process of consent with their relative;

3. Copies of an agreement form for relatives to complete, giving you permission to approach their relative;

4. Envelopes with stamps in which information for relatives can be sent plus reply paid envelopes so that relatives/next of kin/advocates can return the agreement form to you;

5. Posters for display in general areas which should have your photographs on them and information about the proposed study, including the dates of the meetings.

You will also need to set proposed dates for the observation with the manager and senior care team. These dates will need to be included on the poster on display and in the information materials for staff and relatives.

Stage 4: Selecting residents for possible inclusion in the research

You need to discuss with the manager or a senior member of the care team, the residents who could be invited to take part in the PIECE-dem observations. You want to observe people who have advanced dementia, are unable to give informed consent to take part in the study **and** meet one or more of the following criteria

- Cared for in their room
- High level of falls accidents
- High levels of dependency re: communication
- High level of challenging behaviour/un-aesthetic behaviours/sexual behaviours
- Very mobile or agitated residents
- Residents with sight and/or hearing loss

You should exclude residents who are suspicious or who currently have acute physical or mental health difficulties. Therefore, you need to identify as many potential participants to take part in the PIECE-dem observations as possible from all the residents who live in the care home. Although ultimately you only want to observe four people, it will be necessary to start with as large a potential sample as possible to allow for people to decline to take part. This will hopefully mean you can have a choice of who to observe on the day meaning you can then select participants you feel will provide the best picture of care for residents within that home.

The manager/senior care staff will need to send the information sheets, covering letter and reply paid envelopes to the relatives/next of kin/advocate of these residents in order to comply with data protection requirements. If at all possible, a member of the senior team of staff should attend the meetings with relatives. Staff will also need to be given the information sheets and consent forms. Dates of the meetings should be given in the information sheet, along with where to leave completed consent forms.

You should ensure that the posters and further copies of the leaflets are available in prominent areas of the home such as the signing in book, to ensure that relatives, visitors and professionals are made aware of the research study. You should also discuss with managers and senior care staff, your recognition of the possible anxieties that this might raise and highlight the possible need for support to be in place for staff should they need to access it.

Stage 5: Relative and Staff Meetings

It is likely in the meetings you have with relatives and staff that you will encounter some anxieties and concerns because of the nature of the work you are proposing. The meetings should begin with introductions and a brief presentation on the research you are undertaking. It is important to create a clear understanding of the purpose of your research and additionally clarify what it does not do. Both staff and relatives will need to be informed about the expected outcomes of your research. Questions should be encouraged and efforts made to engage staff and relatives in a collaborative process in which you are open and honest about your work.

Staff should be informed that they can decline to participate, and if they do, every effort will be made to ensure they are either: not observed during the time you are in the home; off duty; or in a different area of the home where observations are not taking place.

Relatives can also refuse to give agreement for a resident to be approached. Residents who have capacity are highly unlikely to meet the inclusion criteria to participate in this process, thus you will need to take into account relatives opinions before proceeding with selection of residents.

You will need to take further information sheets, agreement and consent forms to the meeting. At the meeting, identify a date by which you require the forms to be returned.

You will need to arrange a brief meeting with the manager to establish which staff have consented or declined to take part in the research. The manager will need to make a decision about how to manage their staffing arrangements according to this information.

Gaining consent as a member of the care team

Stage 1: Approval to use PIECE-dem

If the PIECE-dem process is being carried out as a part of practice development or an organisational audit or evaluation it may be necessary to gain approval through the relevant governance procedures before commencing with the consent and observation processes.

Stage 2: Introducing PIECE-dem

Once approval has been achieved, your next step should be to arrange to meet with the senior care team to explain PIECE-dem in detail including the inclusion criteria for residents and the process of consent. Once you have agreed to proceed, you will then need to work with the senior care team to explain the process to staff, and the outcomes you expect to achieve. It is likely that staff will have some anxieties about this process. You will need to consider how you can achieve collaboration with staff in carrying out PIECE-dem and what support systems might need to be in place to allay any fears or anxieties expressed within the team. You will also need to identify a date to offer at least one meeting for relatives/ next-of-kin/advocates of residents within the home. These dates should be planned for at least 2 weeks ahead in order that relatives are able to attend. At this point you will need to provide the following materials for relatives/next of kin

1. Information sheets for relatives of residents, including a covering letter explaining the reasons for this contact, and the date of the meeting. This information sheet should also include offering relatives the opportunity to be involved in the process of consent with their relative;
2. Copies of an agreement form for relatives to complete, giving you permission to seek consent/assent from the residents;
3. Posters for display in general areas which should have your photographs on them and information about PIECE-dem, including the dates of the meetings.

You will also need to set proposed dates for the observation with the care team. These dates will need to be included on the poster on display and in the information materials for relatives.

Stage 3: Selecting residents for possible inclusion in the observation process

You will want to observe people who have advanced dementia, are unable to give informed consent to take part in the study **and** meet at least one of the following criteria:

- Cared for in their room
- High level of falls accidents
- High levels of dependency re: communication
- High level of challenging behaviour/un-aesthetic behaviours/sexual behaviours
- Very mobile or agitated residents
- Residents with sight and/or hearing loss

You should exclude residents who are suspicious or who currently have acute physical or mental health difficulties. You will need to identify as many potential participants to take part in the PIECE-dem observations as possible from all the residents who live in your care home. Although ultimately you only want to observe four people, it will be necessary to start with as large a potential sample as possible to allow for people to decline to take part. This will hopefully mean you can have a choice of who to observe on the day meaning you can then select participants you feel will provide the best picture of care for residents within your home.

You should ensure that the posters and further copies of the leaflets are available in prominent areas of the home such as the signing in book, to ensure that relatives, visitors and professionals are made aware of your intention to use PIECE-dem.

Stage 4: Relatives Meetings

It is possible in the meetings you have with relatives that you will encounter some anxieties and concerns because of the nature of the work you are proposing. The meetings should begin with introductions and a brief presentation on PIECE-dem. It is important to create a clear understanding of the purpose of using this process and additionally clarify what it does not do. Relatives will need to be informed about the expected outcomes of your work. Questions should be encouraged and efforts made to engage relatives in a collaborative process in which you are open and honest about your reasons for using PIECE-dem.

Relatives can refuse to give agreement for a resident to be included in the observation process. Residents who have capacity are highly unlikely to meet the inclusion criteria to participate in this process, thus you will need to take into account relatives opinions before proceeding with selection of residents. You will need to take further information sheets, agreement and consent forms to the meeting.

Gaining consent as a senior member of an organisation that has a number of care homes

Stage 1: Approval to use PIECE-dem

If the PIECE-dem process is being carried out as a part of practice development or an organisational audit or evaluation it may be necessary to gain approval through the relevant governance procedures before commencing.

Stage 2: Achieving Collaboration within the Organisation

Preparation of the staff team concerning PIECE-dem is an essential part of achieving your desired outcomes. It is likely that staff will experience some anxieties about the process and its implications for them. It is important to hold one or more preparation sessions with staff to brief them on the purpose of PIECE-dem and the outcomes the organisation wishes to achieve by using the process. During these sessions, staff should be given the opportunity to ask questions and discuss the implications of this for the home, for their practice and for the residents. As not all staff may be able to attend preparation sessions, information materials should also be available, which should contain relevant contact details if they have any further questions they wish to ask. The organisation should give some thought to how staff can be best supported during this process, and make this information available to staff. During these meetings, if appropriate, plans can also be made to set dates to begin the PIECE-dem process.

Stage 3: Informing and Gaining Access

Your next step should be to arrange to meet with the manager and if possible the senior care team in the home. You may need to repeat the process of explaining PIECE-dem, the inclusion criteria for residents and the process of consent. Your next step will be to work with the manager and senior care staff to identify a date to offer at least one meeting for staff working within the care setting and at least one meeting for relatives of residents

within the home. These dates should be planned for at least 2 weeks ahead in order that staff and relatives are able to attend. At this point you will need to provide the following materials for the manager:

1. Copies of your information sheets for relatives of residents, including a covering letter explaining the reasons for this contact, and the date of the meeting. This information sheet should also include offering relatives the opportunity to be involved in the process of consent with their relative;

2. Copies of an agreement form for relatives/advocates to complete, giving you permission to approach their resident plus reply paid envelopes so that relatives/ next-of-kin/advocates can return the agreement form to you;

3. Posters for display in general areas which should have your photographs on them and information about PIECE-dem, including the dates of the meetings.

You will also need to set proposed dates for the observation. These dates will need to be included on the poster on display and in the information materials for relatives.

Stage 4: Selecting residents for possible inclusion in the process

You need to discuss with the manager or a senior member of the care team, the residents who could be invited to take part in the PIECE-dem observations. You want to observe people who have advanced dementia, are unable to give informed consent to take part in the study **and** meet at least one of the following criteria:

- Cared for in their room
- High level of falls accidents
- High levels of dependency re: communication
- High level of challenging behaviour/un-aesthetic behaviours/sexual behaviours
- Very mobile or agitated residents
- Residents with sight and/or hearing loss

You should exclude residents who are suspicious or who currently have acute physical or mental health difficulties. You need to identify as many potential participants to take part in the PIECE-dem observations as possible from all the residents who live in the care home. Although ultimately you only want to observe four people, it will be necessary to start with

as large a potential sample as possible to allow for people to decline to take part. This will hopefully mean you can have a choice of who to observe on the day meaning you can then select participants you feel will provide the best picture of care for residents within that home.

The manager/senior care staff will need to send the information sheets, covering letter and reply paid envelopes to the relatives/next of kin/advocate of these residents in order to comply with data protection requirements. If at all possible, a member of the senior team of staff should attend the meetings with relatives as well as yourself.

You should ensure that the posters and further copies of the leaflets are available in prominent areas of the home such as the signing in book, to ensure that relatives, visitors and professionals are made aware of the research study.

Stage 5: Relatives Meetings

It is possible in the meetings you have with relatives that you will encounter some anxieties and concerns because of the nature of the work you are proposing. The meetings should begin with introductions and a brief presentation on the PIECE-dem. It is important to create a clear understanding of the purpose of PIECE-dem and additionally clarify what it does not do. Relatives will need to be informed about the expected outcomes. Questions should be encouraged and efforts made to engage relatives in a collaborative process in which you are open and honest about your work.

Relatives can refuse to give agreement for a resident to be approached. Residents who have capacity are highly unlikely to meet the inclusion criteria to participate in this process, thus you will need to take into account relatives opinions before proceeding with selection of residents You will need to take further information sheets, agreement and consent forms to the meeting. At the meeting, identify a date by which you require the forms to be returned.

Consent with people living with dementia who are resident in the home

The issue of consent is particularly important to consider when conducting observation where people with dementia will be participants. In developing the consent process we have drawn particularly on the work of Allen (Allen 2001; Killick and Allen 2001), Dewing (2002) and our own considerable experience in conducting research with people with

dementia. The consent process also takes into account the implications of the Mental Capacity Act (2005). You will be the principal person involved in obtaining consent.

From a person-centred perspective gaining consent from people with dementia to participate needs to be a meaningful and inclusive process that takes them seriously as capable persons (Dewing 2002). We intend that the consent procedure is seen as a process rather than a one-off event, with individuals being given information on a repeated basis, and a sequence of opportunities being provided to withdraw if this is their wish. Gaining consent for the PIECE-dem observations in your research will therefore be a four-stage process.

Stage 1: The first stage of the consent process will be for you to meet with the resident's key worker, and where possible their relative/advocate to complete the pre-observation summary. This will only be completed on those residents where their relative has indicated agreement for you to approach them. Whilst a relative or next-of-kin cannot consent or decline on behalf of another person, it would not reflect good person-centred practice to ignore their concerns should any be expressed. Therefore, only residents whose next-of-kin assent to them being approached will progress onto stage two of the consent process. The pre-observation summary will assist you to understand how to approach the resident and assess for signs of ill-being or well-being while you are talking with them. This will help to inform the decision you make.

Stage 2: The next stage is gaining formal written consent to take part. Although capacity to consent is defined in the Mental Capacity Act (2005) as a process that requires individual assessment of capacity for each decision to be made, the inclusion criteria for PIECE-dem is that potential participants should have advanced dementia and be unable to give informed consent for themselves. However, this does not exclude the potential participant from the consent process altogether. Furthermore, you should not assume the resident cannot give consent; capacity to consent should still be assessed as you give information to the resident.

You should be accompanied by a relative and/or key worker in seeking the consent of a potential participant, as if the resident cannot give consent, you will have to make a best interests decision regarding their participation. This best interests decision should involve talking to the person and assessing their reaction to an explanation of the PIECE-dem

observations or to your presence. The relative or staff member will ensure that the potential participants best interests are represented in any decision made.

When seeking consent you need to have a conversation with the potential participant. This should take place at a time when the resident is most likely to be able to concentrate. You have the information leaflet regarding the PIECE-dem observations to support this discussion. You need to check with the potential participant that it is OK for you to spend some time with them talking about the planned observation. If this is granted, or the person shows no signs of this not being OK for them, after a discussion based on looking at the leaflet and in a way that is appropriate to the person and their communication abilities, the person will be asked if they would like to take part.

If the person does not appear to be expressing unwillingness or anxiety about the idea of participating, or of your presence with them, then the member of staff or relative needs to confirm this assessment and provide any further information on whether they feel this is something the potential participant would be happy with based on their knowledge of the person. If they agree that the potential participant does not seem distressed by your presence or to be showing signs of not agreeing to take part in the observations then the member of staff and you need to sign a form. If there is any doubt over the residents willingness to participate, then advice must be sought from the Individual's Mental Capacity Advocate prior to signing. If the potential study participant appears distressed by your presence or discussion of the observations then they will not be included in PIECE-dem observations.

Stage 3 : This stage includes all participants who have agreed initially to take part in the PIECE-dem observations, and refers to subsequent conversations about the process and the participants' willingness to continue, once initial consent has been secured. Each time a period of observation is undertaken, you should reintroduce yourself to every participant and remind them what you are doing. At this point you need to check out that they are still happy to be included.

Stage 4: During the PIECE-dem observations you will assess continually that being observed is not causing distress to the resident. Should you feel that observing a resident is causing them distress you must stop observing them immediately. Should your presence in the care

facility appear to be causing a resident or any other person distress, the observations will be stopped altogether in that area. The assessment of consent will therefore be an ongoing process. You will need to ensure that appropriate measures are employed to alleviate any distress in residents if observations are stopped.

Selecting participants to observe on the day

On the first day of observation you will need to select which four residents you and your co-observer will observe during the two-day observation period. If you have more than four residents who have consented to observations taking place then you should select four based on collecting a representative sample of residents who meet the inclusion criteria and who include physically mobile and immobile residents and where possible those with or without sensory impairments. You sample should also include where possible at least one resident who staff see as 'challenging' and one resident who is seen as 'quiet'.

You then need to follow stage three of the consent process to make sure that each participant is still happy for you to conduct observations on them that day. If they are not another participant should be selected. If they are, stage four of the consent process should be followed throughout all observations.

Preparing the observation process on the day

When you arrive to carry out your observations on the first day, you should swap the posters on display, for new ones which inform residents, staff, visitors and relatives that you are present in the home and what you are doing there. This should include photographs identifying you and your fellow observer. You will need to negotiate with the manager, a private space that you and your co-observer can use during your breaks.

Having completed the selection of the residents to be observed, you should take time to inform staff about your presence and remind them of your role in the home. You should also do this with relatives and visitors who are present during the observation period. It is also important to ensure that other residents in the area you are observing in are greeted and informed of you work in the care setting.

The observation process

PIECE-dem illuminates the experience of those people who are most vulnerable in long term care settings to experiencing a poor quality of life. PIECE-dem is an acronym for:

Person

Interaction

Environment

Care Experience

in Dementia

Prior to commencing observation you will have selected four residents 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. They include those who: are least able to communicate; may be withdrawn; may be at end of life; have bruising or other physical warning signs; are viewed to have high levels of challenging behaviour/un-aesthetic behaviours/sexual behaviours; are very mobile or agitated; have sight and/or hearing loss. The reason for focusing on this at risk group are that they have high levels of need for staff interventions which support their well-being and that if the care they receive is supportive you can be fairly reassured that the care received by residents with lower levels of need receive will also be supportive.

Each observer works with two participants during the same time period, spending time with each participant in 15 minute blocks over a two-day period, covering a typical waking day. This is carried out over two days in order to observe how different staff impact upon the experience for each participant and to observe the resident at key times in their daily lives. It also allows the observer time with opportunities for reflection, to consider what might be occurring for the resident. You will observe 1pm- 9pm on day one and 8am till 1pm on day two, with some flexibility in this to follow the needs of the chosen residents. (See time framework for observation on page 106) Due to observer fatigue it would not be desirable to attempt to complete the whole observation during one day.

Using 1-minute time frames you will make observations of the participants' experiences of the world around them, including recording:

- If the person appears engaged with the world around them or disengaged;

- If an interaction occurs;

- Qualitative notes describing the person's apparent experience of the world around them, what their needs might be, the nature, intention, and experience of interactions and the extent to which apparent needs are met.

Additionally you will take qualitative notes describing the immediate environment within which the resident exists, which includes the extent to which the environment supports the physical, psycho-social and spiritual well-being of the resident.

Your observations of residents will occur in public areas and in hallways. Because PIECE-dem tracks an individuals' experience of care some observations are undertaken in or immediately outside the person's room. This is particularly the case if the resident is spending long periods in bed or is bed-bound. Intimate care activities would not be 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 will include times of high demand for staff interventions, including mealtimes 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. Therefore, as indicated in the time framework for observation, break times are planned to avoid key times of interaction/ activity for residents.

Observations are summarised every 2-3 hours on each resident. By the end of the two days, you will have achieved around four hours of observation for each resident. You will therefore have achieved five written summaries for each resident. These summaries will form the basis of the feedback session you will be delivering to the care team.

Time Framework for Observation

Legend: R = red cell (Resident 1), B = blue cell (Resident 2)

Day 1	1.00	15	30	45	2.00	15	30	45	3.00	15	30	45	4.00	15	30	45	5.00	15	30	45	6.00	15
Resident 1	R		R		R		R		R				R		R		R		R			
Resident 2		B		B		B		B		B				B		B		B		B		
Break											Early Afternoon										Late Afternoon	

Day 1	30	45	7.00	15	30	45	8.00	15	30	45												
Resident 1		R		R		R																
Resident 2			B		B		B															
Break	LA contd						Evening															

Day 2	8 am	15	30	45	9 am	15	30	45	10 am	15	30	45	11 Am	15	30	45	12 pm	15	30	Summary and Prep for Feedback 12.45 to2.00
Resident 1	R		R		R		R					R		R		R		R		
Resident 2		B		B		B		B					B		B		B		B	
Break									Morning											Middle of day

Your conduct during observation

Observation has the potential to be intrusive and to cause worry or distress. It is therefore extremely important that you are mindful of your own conduct during the observation process to minimise disruption to all concerned. When in the care environment you should role model good practice to staff and always remember to treat everyone in a person centred manner.

Unobtrusive observations

You need to ensure that you are as unobtrusive as possible during observation. Therefore, don't take lots of things into the observation area with you. Try just to have the papers you need and a pen/pencil. It is always helpful to carry some extra coding sheets and a spare pencil. Then if someone wants to write alongside you, you can offer them some papers and a pencil. If you take bags, coats and other things into the care areas with you then you look more obtrusive carrying them round and they are likely to be appealing to residents who may want to look in them or take them away. This may particularly be the case of there are few other objects and items for engagement around in a care environment. Don't take anything in with you that is valuable or that you wouldn't want to disappear.

Where you position yourself in the room is also important. You are observing in areas in which people live, they may have their own routines and personal preferences. Sitting in chairs that are used by residents may be problematic, particularly in small spaces where all available chairs are used by residents. Positioning is also crucial in regard to the experience of the resident you are observing. Residents are likely to be aware of your presence. Observing for 15 minutes at a time can be quite intense, so consider how you observe them, and monitor their reactions to your observation.

Observation of residents includes where appropriate, following them at a discreet distance into the hallways and other areas of the home as well as sitting and dining areas. However it would not be acceptable to be present when the resident is receiving intimate personal care. During these occasions, it may be appropriate to stay near their bedroom or bathroom and discreetly observe their reactions prior to and after they have received care. If a resident moves around a lot, you may have to consider when to follow them, or where to sit in such a way that you can observe them unobtrusively during the period of observation.

Observing in bedrooms

Some participants you observe using PIECE-dem will be bed-bound and may be being cared for in their own room. If this is the case then it may be acceptable for you to carry out observations in their bedroom. However, if you do so you should ensure the following:

- This is not upsetting for the person;
- No personal care is being carried out;
- The person does not have visitors;
- Your observation is not off-putting for a staff member or the participant, for example causing the person to behave differently e.g. putting them off eating.

What if people talk to me?

You need to remember that you are a role model of good practice. Therefore, it would not be appropriate for you to ignore anyone who wanted to talk to you in the care environment. When carrying out observations, as well as being prepared to answer questions yourself, you should always arrange for a member of staff who is on shift on the unit you are observing on, who can answer any questions from relatives or visitors. as well as answering questions yourself. Residents, including the person you are observing may want to interact with you, particularly because you are present in the home for long periods of time. It is important to engage with questions or conversations while trying to maintain a balance with the purpose of your work in the home.

Our experience is that it is likely that you will on occasions need to engage to some degree in what is going on around you, particularly in smaller lounge/dining areas. If there is a group activity occurring, for example singing or exercise, it may be appropriate to have some involvement in this. You will need to reflect and monitor your impact upon the residents and the environment and adjust your position/behaviour to achieve a balance between your observation and maintaining a person-centred approach.

> *Lily was sitting in the lounge in front of the television. It was evening time and a member of staff was in the room but attending to another resident. You were observing Lily when she looked at you and spoke to you and then tried to get up to walk over to you. Lily seemed unsteady so you got up to support her, and asked her if there was something she needed. You continued to talk with her until the member of staff was able to join you and take over and it was appropriate for you to withdraw.*

Your responsibilities in regard to safeguarding

It will be necessary to ensure that prior to commencing the process of engaging with PIECE-dem, you are familiar with your responsibilities concerning safeguarding of vulnerable adults in the area you are going to be working within. Your responsibility to ensure that the well-being of residents is upheld is paramount and should you witness any action which causes you to be concerned about the welfare of a resident, you are obliged to respond according to the local policies and procedures. Should you witness for example:

- Action or inaction that causes the resident to be at risk of harm or experience harm
- Long periods of unattended or admonished distress
- Deprivation of liberty

Then you will need to cease observations, consult with your co-observer and agree an appropriate course of action.

Coding resident experience

Person, interaction and environment

The focus of this observational process is to try to understand the experience for the person living with dementia, of the world around them and the extent to which it supports their well-being. The PIECE-dem process has been developed through analysis of literature, in-depth interviews, and focus groups and subsequently supported by detailed observations of the experience of people living with dementia who have significant levels of need, and reside in care settings. Through this process, it has been identified that there are a range of indicators of positive, person-centred practice in which the person living with dementia receives care which appropriately supports their psychosocial, spiritual and physical needs (**Table A**).

Table A: Examples of Indicators of Positive Person Centred Practice

Person	Interaction	Environment
Uninhibited Behaviour *"I think bursting into song is one thing that you sometimes experience with some people, that's not going to happen when they're not feeling comfortable."*	**Knowing the Person** *"I watched a member of staff come into the room with a gentleman who liked a particular sort of music, she went over to the stereo, put a record on that he liked, and danced with him and she danced with him to the toilet"*	**Environment supportive of needs** *"The layout of the environment is really supportive of this (residents interacting with others), no chairs lined up round the walls, chairs in clusters which facilitate interactions together"*
Not Withdrawn **"***Well withdrawal is the big one, (wife) has come out with the right care"*	**Social engagement Staff/Resident** *"Sharing humour"*	**Environment individualised** *"Good physical environment with lots of visual stimulation; sound that is achieving something – so not having the TV on just for something for people to look, at"*
Autonomy of Actions *"free to move about and touch things and move things"*	**Responding to Residents** *"There is one woman there who does a lot of shouting, and when she starts shouting the care worker will go up to her and say 'right *** what's the matter?', go and sit by her, quieten her down and she's fine for another couple of hours"*	**Protective technology** *"We put sensors on his door, staff were alerted if he moved, and also on the door of the vulnerable person. That was protective"*
Physical Care *"hair and nails are cared for"*	**Residents Engaged with Others** *"People talking with each other and staff – it may not be a logical conversation but they are interacting with others"*	**Opportunity to engage with the world** *"It's not just about being able to see the outside world, it's about being able to access it"*
Physical appearance well maintained *"Appearance is appropriate for person"*	**Facilitating autonomy/freedom** *"One lady actually went out in the snow, even though staff were absolutely terrified, this lady really wanted to go out and had always go out... that's respecting that person's want to do that and it spoke volumes to me because it's not often that people would be allowed that risk"*	**Opportunity to Engage with Possessions/Objects** *"A good sign is where people seem to have possessions, it's sad that we have grasped on rummage bags and clutter but that's what we mean, things that people can touch and move that gives them a sense of purpose"*

It is also evident that there are a range of indicators that would suggest that the person experiences poor care, which does not meet their needs and can result in abuse, neglect and loss of dignity (**Table B**).

Table B: Examples of Indicators Leading to a Risk of Abuse Neglect or Loss of Dignity

Person	Interaction	Environment
Unattended Distress *"We might see distress in someone's face, the way someone is moving or the way someone is articulating and shouting, and to not acknowledge that would seriously worry me"*	**Short tempered Staff** *"A bit snappy and short tempered, she would shout 'oh shut up'"*	**Freedom to Move** *"All the residents are in the same room together"*
Unattended Withdrawn Behaviour *"So I would be concerned if they were sitting in their seat and it was obvious that nobody had come to engage with them for a very long period of time"*	**Issuing Orders to Residents** *"People being told to sit down, people being in their chairs the whole time frightened to actually stand up"*	**Lack of or Regimented Activity** *"Activities are regimented and not personalised, e.g. the half hour of bingo that no-one engages in"*
Physical Appearance not Maintained *"Resident's appearance isn't very well kept"*	**Individuality not Acknowledged** *"A younger person with dementia - had always worn his hair long and the care home staff tried to have his hair cut"*	**Lack of Available Aids to Support Independence** *"Lack of appropriate facilities to support eating and drinking"*
Wariness Towards Staff *"When a resident is sitting in the chair and staff are walking by, you can tell that some residents can be very wary of certain staff and someone that's been chatting quite freely will suddenly shut up when a certain member of staff comes by – you can see a change in that resident, you can sense that they are uneasy in that environment"*	**Staff Manipulation/Holding Power** *"There was a lot of manipulative behaviour between the staff and the smokers about when they could have them and when they were allowed to smoke"*	**Homeliness of Environment** *"Clinical feel no attempt at homeliness"*
Physical appearance – Unkempt *"Un-cleanliness. Lack of dignity, faeces in the nails"*	**Labelling/Objectifying** *"So the manager said she would tell me which residents I could speak to, we went down to the room and she said 'she can talk, she can talk, she can talk, she can't talk"*	**Noise Levels** *"High level of noise, e.g. from television or radio"*

As you will see from the above tables, these factors are grouped around three main themes, PERSON, INTERACTION and ENVIRONMENT. Additionally an overarching concept of POWER is central to understanding the experience for the person with dementia, in relation to their power to influence their care experience and the way in which power is used to deliver care. These concepts form the focus for the observation using PIECE-dem. Your structured observations are focused upon observing the person in relation to:

- Their attempts to express their psycho-social, physical and spiritual needs;
- Their expression of their experience of the world;

- The interactions they initiate and experience from others including considering the 'act' of the interaction, what it appears to be designed to achieve (intent) and the impact upon the person;
- The psycho-social, spiritual and physical environment surrounding the person and the extent to which this facilitates the meeting of their well-being.

Your observations should consider the use of power in all of the processes occurring during observation in relation to each person you observe. You need to remember that the focus of your observation is to capture the extent to which the care setting supports the person's well-being and is therefore preventive, or contributes to a risk of experiencing abuse, neglect or loss of dignity.

Completing the raw data sheet

You will find a raw data sheet in Appendix 1. The PIECE-dem coding focuses on three different engagement types accompanied by detailed notes in two separate sections. So in each 15-minute time frame you will be:

1. Recording interaction, engagement and disengagement during each minute of observation;
2. Making qualitative notes concerning the minute-by-minute experience for the resident of the world around them;
3. Making qualitative notes concerning the immediate psycho-social and physical environment surrounding the person.

Completion of the raw data sheet involves observing each resident for a total of 12 minutes in any 15-minute time frame. The additional three minutes are to ensure you have completed your observational notes, and to transfer to the other resident to be observed. Should a particularly important interaction occur when you are due to finish observing, you can carry on and record for a further 15 minutes, however this should be balanced with spending a similar amount of time with the other resident you are observing. See Appendix 4 for an example of a completed raw data sheet.

Recording engagement, disengagement and interaction

Interaction

Interaction can be verbal e.g. spoken words or sounds, or non-verbal e.g. gestures, facial expression, eye contact. If you observe any interaction with another person or object during the time frame then you should record a tick in the 'Interaction' box for that minute.

> *Beth was sitting in her chair holding a doll she called Ruby. She held the doll tenderly and placed it on her lap. She spoke to Ruby, smiling and encouraging her while she changed her clothes. This was recorded as an interaction during the 4 minutes that it occurred.*

Engagement

When coding engagement you are looking for signs of activity or responsiveness to others or the physical environment surrounding the person. Examples of engagement include: walking, rubbing, touching, grooming, singing, eating, talking, calling, moaning, holding, looking, touching or manipulating an object. It can also include passive engagement such as watching what is going on, or attempts at interaction which achieve no response in return. If any engagement occurs during the time frame you should tick the 'Engaged' box.

> *Kath was sitting in the dining room, having just finished her pudding. She was looking around the room, and then looked down to her dish. She held her napkin and began to 'clean' the dish, rubbing and wiping the bowl and her spoon. She put it down and folded the napkin up and sat back in her chair.*

Disengagement

You should only record a person as disengaged if they are not engaged in any type of interaction, activity or other engagement during each one-minute time frame. Disengagement can involve sitting with eyes closed but not appearing to be asleep, sitting with eyes open but not appearing to be focused on anything in particular, staring into the

middle distance or sleeping. If the person is disengaged for the whole of the time frame then you tick the 'Disengaged' box.

> *John communicates solely with eye contact, gestures and occasional noises. A powerful episode of eye contact between a member of staff and John had just finished, John sighed and closed his eyes. His eyes remained closed for 3 minutes even though his breathing and his posture did not suggest that he was asleep.*

Notes

Completion of the minute-by-minute notes section offer an opportunity to provide details to support the coding of engagement, disengagement and interaction, and to further enhance our understanding of the persons experience, through attempting to understand their expressions of need, feelings, actions, interactions with others or objects and their experience of their immediate environment. There is clearly potential for recording large amounts of qualitative information. Therefore we have structured the notes so as to capture information that helps us in particular to consider abuse, neglect and loss of dignity and the aspects of care that lead to care that does or does not promote or support such things. Qualitative notes should address the following:

Person

Two major challenges are evident in observation with people who are highly vulnerable and experiencing significant levels of disability:

1. That levels of disability engendered by dementia and other co-morbid illness can make expression of need very challenging for the person and thus difficult to interpret for the observer;
2. You will not necessarily know the person with dementia, and thus you will not always able to make an interpretation of what might be being expressed by them. While this may improve as observation of the person progresses, it is still challenging.

Thus the observer will need to consider overall whether the person's physical, psychological, social and spiritual needs are being met, reflecting upon the whole range of needs that might be evident to achieve well-being. Recording of possible expressions of need should be always be tentative and reflect upon the information received in your pre-observation summary. These expressions may include small gestures or movements, for example:

> *Peter spends his day being cared for in a reclining chair. You have been observing him for nearly 2 hours, during which time he has remained in the same position. You notice that occasionally he lifts his bottom and legs up and down. Over the next 15 minutes this happens on a number of occasions. You note down that you wonder if he is uncomfortable and is trying to shift his position.*

Thus you should record actions (and their possible intention) that may be observed/ expressed by the person with dementia. This includes their facial expression, body posture, bodily movements, attempts at communication, vocalisations.

Interaction

Summarise interactions occurring and consider which needs these interactions addressed. Key things to record include any direct action of another as it relates to the person with dementia. Therefore the nature of the interaction and how this appeared to be experienced by the person with dementia is recorded, as is the posture, tone, content, apparent intent, and use of touch occurring in the interaction. An act may not result in an obvious impact, however it should still be recorded. You will also make tentative comments on whether you felt interactions achieved a connection between the person with dementia and the other involved in interaction.

Environment

Finally, during your observations, you may also need to include relevant notes concerning the immediate physical and psycho-social environment surrounding the person with dementia. This will include considering whether pressure relieving aids are present for someone who spends a significant period of time in bed or lying in a chair, and if so, whether they functioning. Or if there are key objects present in the environment that support that person's well-being.

> *Mrs Lewis appeared to be asleep in her chair for the whole of the 15 minute period of observation. She had a soft toy next to her, which she held onto while asleep. Her facial expression appeared to be calm and peaceful. Later in the observation you noticed she was asleep without her soft toy, her sleep appeared disturbed and her facial expression seemed distressed.*

Immediate environment

Prior to and during observation, summarise the immediate physical and psycho-social environment surrounding the person with dementia in relation to their sensory experience, the management of the environment and the physical environment and the extent to which it appears to support the person's needs. This should include what the resident can hear, see, smell, experience from where they are. How does this environment support their physical, psycho-social and spiritual needs?

> *Kate was sitting slouched in her chair next to a large television which was on. No-one in the room appeared to be watching it. Kate appeared to be asleep. A Cowboy film came on, with the first scenes being a gunfight, with lots of loud bangs and shouting. Kate awoke with a start, and a cry of alarm, she appeared distressed and frightened, and held her arms around herself rocking backwards and forwards. No-one appeared to notice her distress.*

Data analysis

Data summary

As you will see from the Time Framework for Observation (page 106), approximately every two hours you will take a break from observations for half an hour. As well as achieving a break from observation and to replenish your needs, the purpose of the break is to achieve a summary of the time period for each resident and additionally, to provide an opportunity for you to reflect upon your observations with your co-observer.

You will find the summary sheet in Appendix 3, and additionally a completed sheet as an example in Appendix 5. You will see that the questions you are asked assist you to focus upon the experience for the person with dementia. This includes their expression of need and the extent to which their needs were met, their experience of interaction and whether a connection was made. It also requires you to consider the extent to which the environment around them supports their well-being. It is important that you keep in mind as you summarise your observations, that this process is designed to develop an understanding of the extent to which the care supports or detracts from well-being, and thus renders the person at risk of abuse, neglect and loss of dignity. Additionally you also need to consider the influence of the use of power during your observations, noting whether the person was enabled and facilitated to take personal control to the extent that they are able, or whether they are subjected to routines and activities in which they have no control.

You will see that the final three sections on the summary sheet require you to reflect upon your experience of observation, the experience of staff and any other comments you may wish to make. The importance of reflection in this process cannot be understated. This is particularly the case in poor care environments where you may witness experiences of distress which can be painful and powerful. Without making time for reflection, it is possible that you could respond by normalising the experience of the residents and therefore downplaying the significance of your observations, or alternatively viewing the whole experience as poor. It is necessary for you to ensure that breaks are taken and that you use this opportunity to discuss any thoughts and reflections you might have. In addition, it may

be helpful to have someone independent of the process who you can contact should you have any concerns that you wish to discuss.

Making sense of the results of the tool

At the end of the analysis you will have two primary sources of data:

1. A numerical summary of the periods of engagement, interaction and disengagement
2. Qualitative notes concerning the residents experience of their world

You will also have five summary sheets, which will assist you to make a judgement about the resident's experience during your observation.

Feedback to the staff team

1. Feedback should be tentative, particularly if you don't know the residents (haven't worked in the home before) and begin with an exploration of the perceptions of the staff concerning your work, how they experienced the observation and what they noticed about what was going on during the observation process;

2. Begin with some general feedback concerning the experience of the residents and your perceptions of their experience of the world, if at all possible start with positives and use examples from your observations to illustrate this;

3. Summarise your observations of each of the four residents and their needs. Again, begin with the positives and move on to areas which need addressing. Use summaries of the numerical data on numbers of times engaged/interacting but in context of qualitative notes which give further detail concerning these figures;

4. This structured feedback should be based on the questions asked in the summary sheets, so explore:

   a. The person's apparent experience of the world including indicators of well-being and/or ill-being. This is particularly important for people who are unable to express their experience of the world verbally and should include your observations of their non-verbal expression;

   b. Opportunities for the person to exert control/or be supported to take control;

c. The use of power in engaging with the person, through interactions and actions;

d. Your observations concerning the physical, spiritual and psycho-social needs and the extent to which these were met;

e. Interactions and connecting;

f. Environment;

g. Staff experience of the person.

Give examples of the issues you are raising to highlight and create opportunities for this to be a discussion.

Agree an action plan for each of the residents/practice within the home at the end.

Appendix 1: PIECE-dem Raw Data Sheet

Participant no.   **Time Start:**   **Time Finish:**

Table 1	1	2	3	4	5	6	7	8	9	10	11	12	Total
Interaction													
Engaged													
Disengaged													

Time Frame Notes
1
2
3
4
5
6
7
8
9
10
11
12

Immediate Environment

Appendix 2: PIECE-dem Pre-Observation Summary Questions

Participant No:

Daily life: What is this person able to do for themselves? What does this person need help and assistance with? What does this person enjoy doing? Who this person like spending time with? Does this person have spiritual beliefs that are known about?
Understanding the person's needs: How do you know when this person is happy and content? How do you know when this person is unhappy or uncomfortable with what is happening to them? How do you know if this person is experiencing pain?
Health: Does this person have a diagnosis of dementia? Do you know what type and when this was made? Does this person have any physical illnesses or problems that affect their daily life? What medication is this person taking currently?
Life before coming to the home: What roles have been important to this person during their life? What influence do these roles and their history have on their behaviour now?

Appendix 3: Summary of Observation Block

Participant Number:

Tick which observation block you are summarising

Early afternoon	Late afternoon	Morning	Middle of day

Record number of minutes spent in each category					
Interaction		Engaged		Disengaged	

Summarise your perception of the person's predominant experience of their world during this time period.

To what extent was the resident able to exert control within their world and how was this achieved?

How were the person's physical needs met?

How were the person's psycho-social and spiritual needs met?

When do interactions occur, who is the interaction with, what appears to be the purpose of these interactions and what impact do they have upon the person with dementia? Was knowledge of the person used in the interaction?

Was an empathic connection made during interactions between staff and resident? (describe how this was achieved and if not, why it appeared not to occur)

What facilities were present within the environment to support the person's identity, occupation and inclusion? Were these facilities made use of in interactions with the person?

What emotions did you experience during this period of observation and why?

How do you think the staff experience this person?

Appendix 4: Example of completed raw data sheet

PIECE dem Raw Data Sheet. Participant no. Ellen   Time Start: 10.53   Time Finish: 11.08

Table 1	1	2	3	4	5	6	7	8	9	10	11	12	Total
Interaction		x	x						x				3
Engaged													
Disengaged	x			x	x	x	x	x		x	x	x	9

Time Frame Notes	
1	Ellen continues to sit in the dining room, eyes open but staring into space
2	Carer moved her chair and asked Ellen to stand up, she didn't warn her that this was going to happen, Ellen appeared shocked. Carer took her arm and walked her towards
3	the door, Ellen was walking at a pace that appeared faster than she could manage, and the carer was walking in front of her and didn't appear to notice til the last minute that Ellen was walking towards a door frame. Ellen appeared upset and alarmed. Carer sat Ellen down in a chair in the hallway.
4	Ellen tried to get up; Carer moved her chair without telling her this was going to happen. She remained in the chair, looked down towards the floor after the action of the member of staff.
5	Ellen sitting in a chair, facial expression suggests she is distressed or sad, not engaged.
6	As 5
7	As 5
8	As 5
9	Carer interacts with Ellen and asks if she's ok, bends down to her eye level. Asks her what's wrong, Ellen doesn't respond to this, continues to look into space, staff moved away.
10	Sitting in a chair appears withdrawn, looking down towards the floor, eyes half closed, body posture appears quite tense, arms folded.
11	As 10
12	As 10

Immediate Environment
Still in the dining room, in a chair. Radio still on, on heart fm, next to her table. No evidence of social interaction, or engagement with other residents in the room. She is sat in a chair which is not supportive given that she appears sleepy. Has been in the dining room since before 8.30am. Hallway she moved into is dark and has little to offer stimulation; her soft toy is not by her chair as it was yesterday.

Appendix 5: Example of a completed 2 hourly Summary

Summary of Observation Block   Participant Number: 05

Tick which observation block you are summarising

Early afternoon	Late afternoon	Morning	Middle of day ✓

Record Number of minutes spent in each category					
Interaction	15	Engaged	24	Disengaged	11

Summarise your perception of the person's predominant experience of their world during this time period.

John seemed at times to find it difficult to make sense of others intentions and the world around him. He sometimes appears concerned about what is happening, for example he sometimes frowns and pulls at his trousers when an interaction occurs. He sometimes says no to attempts at interaction or intervention, but is not angry with carers when they occur. So is this about his capacity to process information and understand?

To what extent was the resident able to exert control within their world and how was this achieved?

John seemed to have some capacity for taking control, but his difficulties with language seemed to be a source of frustration for him in this regard. He seems to exert control when interactions are attempted by carers, by saying no, or appearing to consciously ignore something someone is saying to him. He pushed his cup away from him when he had finished his tea, despite being prompted to continue to drink. Carers didn't always appear to accept no from him when they wanted to do something for him.

How were the person's physical needs met?

His physical needs for a safe transfer from chair to wheelchair seemed to be met appropriately; he did not appear concerned at all about this process. He was offered a number of drinks during the 45 minutes I was observing him. I did not see evidence of him appearing uncomfortable during the time I observed him and he was encouraged to walk a little way from the chair to the wheelchair.

How were the person's psycho-social and spiritual needs met?

Johns psycho-social needs in regard to relationships appeared to be met while I was there, as his wife came to visit and had lunch with him. He appeared to recognize her and was more alert and responsive when she arrived. However his need for enriching activities did not appear to be met, he spent a fair proportion of time appearing to seek interaction without receiving it, looking around and trying to engage eye contact with others with little success.

When do interactions occur, who is the interaction with, what appears to be the purpose of these interactions and what impact do they have upon the person with dementia? Was knowledge of the person used in the interaction?

Interactions with Carers focused mainly on tasks to be completed. These were explained to him in some detail, but he often said no, which made me wonder if he understood what was being said to him. On one occasion, a carer made a considerable effort to talk with him and his wife, and he

smiled and laughed with her. Additionally he seemed much more animated with his wife, laughing and talking with her. However, there were occasions when carers talked over him, particularly when serving out dinner. He was not offered choice about what he wanted for dinner, and his wife indicated that he didn't like what he had been given. The carer was happy to change the meal offered at that point.

Was an empathic connection made during interactions between staff and resident? (describe how this was achieved and if not, why it appeared not to occur)

Interactions with carers seemed to rarely achieve a real connection with him. Where they were successful, the staff member had spent time bending down and attracting his attention for quite some time before explaining what he wanted to do. His wife did seem to make a connection with him, particularly when she showed him photographs of his grandchildren and she also took some time with him, patiently explaining what the event was that had happened.

What facilities were present within the environment to support the person's identity, occupation and inclusion? Were these facilities made use of in interactions with the person?

Little evidence of facilities that could support his identity and occupation needs. He did look at the newspaper at one stage, but seemed to struggle with this, I felt that this maybe too complex for him. While carers used his name, and talked with him, they didn't appear to know much about him. His wife showed him photographs and this seemed to be particularly enjoyable for him. She talked about family and he responded to this with gestures and nods and pointing at different people and their pet dog.

What emotions did you experience during this period of observation and why?

I felt quite frustrated because it seemed as though he could enjoy some activities and engagement but that he needed extra help with communication. He seemed to feel frustrated at times, (was I mirroring this?) wanting to engage and not being given the opportunity and I am concerned that there is a real risk of him becoming withdrawn if his attempts at communication aren't responded to.

How do you think staff experience this person?

It seems as though he came with a history of being challenging, from the home he was in previously and I wonder if carers find him a bit difficult to communicate with/ are worried about doing the wrong thing. Maybe they also are worried because they also know I am watching. A couple of the carers made a particular effort, one of the male carers interacted with him and his wife during dinner and seemed to make a connection, so seem to feel less concerned about interacting with him.

Other comments

How much is known about his life history and his occupation? Is there a way of involving his wife in working with him?