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Privacy and Dignity in Continence
Care for Older People

REPORT ON PHASE 1

September 2008



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Funding and acknowledgements

We would like to thank Dr Adrian Wagg and Dr Jonathan Potter of the Royal College of Physicians and also Dr Danielle Harari from the British Geriatrics Society for their help and financial support. Thanks also to the wider steering group who formed the expert panel and the participants without whom this report would not have been possible. Thanks to Tara Chapman for her input whilst a researcher on the study.

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1 Introduction

In recent years dignity in care has become a priority and the focus of a number of government reports and policy initiatives. (DH 2003, 2007), (SCIE 2006). The National Service Framework for older people (DH 2001) and its follow up document, (DH 2006a) for example stated that maintaining dignity was pivotal in improving care for older people. However, despite this political support, there continue to be problems in health and social care settings related to preserving the dignity of older people (Levenson 2007). There is a risk therefore that generalised policy statements have little effect on actual practice and care unless they are operational, and supported by detailed guidelines for practice.

Alongside policy, there has also been an increase in studies of dignity in health care (Chochinov et al,2002a), (Woolhead et al 2006) particularly focusing on the ways in which dignity is defined and what it means to people. There have, however, been far fewer on the relationship between dignity and personal care particularly when care involves sensitive issues such as incontinence. This report provides an initial analysis of emerging themes and findings from Phase 1 of the study of privacy and dignity in continence care for older people funded by the Royal College of Physicians and the British Geriatrics Society.

The overall objectives of this two year project are to:

- i. develop reflective standards/guidelines for dignified care,
- ii. produce recommendations for best practice,
- iii. provide advice with regard to changing practice in the clinical setting.

There are three phases to the project:

Phase 1: Standards that constitute dignified bladder and bowel care will be developed using a literature search supported by focus groups and interviews with older people.

Phase 2: An observational schedule will be developed and piloted and a study will be conducted to develop and refine person-centred attributes of dignity in continence care through a validation process in acute and care home settings.

Phase 3: The development of recommendations for best practice with support tools for enhancing practice using a validation process with continence and dignity experts.

2 Literature Review

Using contemporary literature, this review focuses on three main areas to rationalise the approach for the first phase; namely dignity and older people, dignity and continence, and dignity and care.

2.1 Dignity and older people

The concept of dignity refers to individual maintenance of self-respect and being valued by others. Dignity has been analysed from the older person's perspective in several studies, see for example, (Mairis 1994; Walsh and Kowanko 2002; Woolhead 2004), and has been defined as a multi dimensional concept embracing dignity of identity, human rights and autonomy and behaviour. These commentators suggest that it is easier to specify when dignity has been compromised, for example, when older people are treated as objects, patronised and excluded from decision making. Within care systems, dignity can be challenged through negative interactions with health care providers, a lack of concern for privacy and general insensitivity for the needs of vulnerable older people. Despite the wealth of literature around this subject, dignity remains a vague, ambiguous and highly abstract concept (Griffin-Heslin 2005). Street (2001) also argues that dignity is socially constructed and that as it is subjective, situational and contextual, it is difficult to define. Consequently, the maintenance of dignity has become difficult to translate into explicit patient-centred practice interventions, especially in older people's care (Jacelon et al 2004).

Some studies have made specific contributions to our understanding of dignity in relation to older people. Woolhead et al's (2004) qualitative study identified several themes relating to dignity including identity; self-respect/esteem, (integrity, trust) human rights, (equality and choice) and autonomy (independence, control). Mairis (1994), examined dignity from the perspective of healthcare professionals and found that dignity was linked to behaviour. The study suggests that dignity exists when individuals are capable of having control over their behaviour, the environment and the way they are treated by others. Jacelon et al (2004) noted that the loss of self control or a sense of calm or composure is perceived as being undignified. Both studies have interesting perspectives in that what actually constitutes dignity may be differentially felt by staff and patients.

2.2 Dignity and continence

Care for people with bladder and bowel problems is a sensitive matter, whether it is provided in the community or in an institution and preserving privacy and dignity during such care is an essential feature during this process. Many people with bladder or bowel problems present late to health care (Horrocks et al 2004) and may be easily discouraged by negative experiences. The National audit of continence care for older people (RCP 2005, 2006) set out to measure adherence to standards of care for the preservation of privacy and dignity in care for older people. The measurements however, referred to very broad indicators such as: number of

pads available, limitation of catheter use, training for staff and the provision of facilities which might be perceived “private”. Chochinov et al’s (2002a) study of cancer patients who were receiving palliative care highlighted the relationship between dignity and continence problems. A total of 213 patients were asked to rate their sense of dignity on a seven point scale. Those who indicated that ‘loss of dignity was a significant concern’, were statistically significantly more likely to have difficulty with bowel functioning and heightened dependency (i.e. incontinence). This reinforces the need for more research that looks further into the association between dignity and continence care.

Billings & Brown (2006), in a study commissioned by the Clinical Effectiveness and Evaluation Unit of Royal College of Physicians in preparation for the National Audit examined the user and carer perspective on continence. The project sought to reveal the importance older continence service users attached to a range of standards, developed in conjunction with users. The study adopted a semi-structured interview design, and issues of dignity emerged as a predominant theme. This study made an important contribution in a number of ways. Firstly, it revealed that the maintenance of dignity was seen as paramount by older people but easily eroded by a number of quite specific factors including the attitude, conduct and assessment skills of professional caregivers, lack of gender-specific or appropriate amenities, and ill-fitting pads. All of these factors were in turn connected to self-esteem, confidence and control and articulated not only by service users, but witnessed by their carers.

2.3 Dignity in care

While there is much discussion about what constitutes dignity, there is a lack of detail about what constitutes the promotion and maintenance of dignity for the older person in a caring environment. Standards of care, for example, invariably choose ‘dignity’ as an overarching criterion without clearly specifying its components (DH, 2004). The lack of focussed guidance in turn creates inconsistency in practice and a potential mismatch between professional views and the user experience, as demonstrated in the National Audit. Even in the established broader indicators for good practice in continence services, which covers the identification, assessment and care of people with incontinence (DH, 2000), there are only vague guidelines as to how to achieve best practice. Wagg et al (2005) conducted an audit of continence care in the UK and found that 68% of 195 hospitals in England and Wales had no written policy for continence care.

Few studies have bridged the gap between theory and practice, and the majority of these have been focused on those who provide the care rather than users and carers experiences. Jacelon et al (2003) made broad suggestions for how care can be ‘dignified’ in areas such as rehabilitation (Stabell and Naden 2006) and accident and emergency (Griffin-Heslin 2005). Birrell et al (2006) include the consumer perspective, identifying seven factors that focus on respect for the individual in palliative care, compiled through staff and patient views of privacy and dignity. These factors focus on attitudes,

boundaries and privacy, but again there is a lack of specificity and they could be open to interpretation. However, these studies show that looking at one particular area of care has the potential to reveal specific and relevant components of dignity to assist practice. Franklin et al (2006)'s research, explores dignity purely from the viewpoint of older people in the under-researched area of nursing homes, and includes continence problems. The research described how loss of control of the body in elimination, often made residents feel unclean with the body being unrecognisable or shameful because of the way it behaved, looked or smelled. Lack of information about how best to meet an older person's needs and desires meant that often such needs were not met. The third theme was of inner strength and a sense of coherence in older people with their strategies for coping within a nursing home. Supportive attitudes from both staff and next of kin strengthened older people's possibilities of maintaining dignity of identity.

A number of authors add to this; Walsh and Kowanko (2002), for example, reported that patients felt dignity was maintained when they were given choices and had an element of control over aspects of their care; Woolhead et al (2004) described how older people felt treated like objects when their views were not consulted; and Lothian and Philp (2007) stated that giving older people and their carers adequate information to allow them to make choices about care increased their autonomy. Respect for people within the caring environment and attitudes of staff and next of kin has therefore demonstrably been shown to help maintain a feeling of dignity.

These studies have been very informative in starting to define the concept of dignity in healthcare, and some have made specific links to continence issues. Whilst patients and staff may have different views of dignity, understanding the conceptual definition from both viewpoints may eventually lead to new and better healthcare standards. Previous studies offer some direction, and this phase of the project will start to tackle the deficits in current understanding. In summary:

- Knowledge is limited to commentary and broad description of the pathways care should take to achieve dignity, and little is understood about how dignified care can actually be undertaken and achieved. There is a need to reveal more about practice behaviour and the wider influences in the caring environment.
- Focusing on specific areas of care has the potential to assist in delineating components of dignified care.
- The importance of continuing to include the user perspective is also paramount to counter the largely professional orientation of existing knowledge, and will be important in uncovering discrete dignity variables associated with continence to take forward to the second phase.

3 Methods

3.1 Research approach

This phase was concerned with exploring what dignified care meant to older people who have continence problems using exploratory qualitative methods in order to establish user derived indicators of dignity. The aim was to elicit more clearly the meaning of dignity in relation to aspects of continence care and take this forward to phase 2. The literature intimated that the primary areas to select a sample group from should be nursing homes and older people in hospital, as lack of provision of dignity in continence care has proved to be particularly evident in these settings.

Individual semi-structured interviews were used to involve older people in this phase of the project. It was originally planned to undertake focus groups with hospital patients, however due to their frailty, this was not possible. Qualitative research is particularly suited to older people, and can be encouraged through the use of prompts and scenarios to express a more personal or alternative view (Burnside et al 1998). In addition, Billings and Brown (2006) found that individual interviews with older and frailer users were productive, allowing the researcher to respond to the particular cognitive ability of the participant and maximise conversation.

Ethical approval was obtained from the London MREC in June 2007.

3.2 Areas

The project was conducted in two areas - Camden and Islington and East Kent. It included residents from two nursing homes per area and older people in an acute hospital setting in each area (total of four setting). The areas were in two contrasting parts of Britain in terms of socio-economic profiles and health experiences.

3.3 Sample

The sample was a purposive mix of people aged 65 years and over. Other inclusion criteria were that the participant had to be cognitively and linguistically able to participate in the interview or focus group, and had any of the following:

- urinary and/or faecal incontinence;
- requiring assistance with toileting;
- assistance with the use of maintenance products or
- assistance with catheter or bowel care.

It was important to capture a range of experiences relating to continence and therefore include people with a range of continence problems that also spanned over different lengths of time. Someone with long-term continence problems for example would feel a loss of dignity differently perhaps to someone experiencing sudden temporary incontinence.

A total of 33 interviews, 15 from nursing home residents and 18 from hospital patients was achieved. Participants fulfilled the research criteria – all were over 65 years, with a continence problem and able to give informed consent. The ages of the participants ranged from 68 – 89.

Phase 1 Participants

	NH1	NH2	NH3	NH4	H1	H2	Total
Male	5	1	1	3	1	2	13
Female	0	3	2	0	3	12	20
Total	5	4	3	3	4	14	33

3.4 Access and recruitment

The researchers approached the prospective participants through a third party, namely a key worker. In each setting, nurses and care workers were informed of the project through either direct contact or through a senior member of staff. Information sheets for staff were also provided (appendix 1). Regarding access to participants, in the case of the nursing homes, the manager approached selected participants who fulfilled the research criteria and gave them a project information sheet (appendix 2). In the hospital setting, either a junior doctor or a nurse did this. If the potential recruits expressed an interest, the researchers then went through the information sheet with the person and gained consent. Recruitment was difficult due to the frailty of our target group in both settings. A number of people who had manifested interest in taking part actually decided not to participate either because their condition was unstable, they did not wish to speak about their continence problem, did not recognise they had a problem, or felt they had nothing to say.

3.5 Instrumentation and data collection

The interview schedule was constructed around the aims and objectives of the project using the literature as a basis (appendix 3). The schedule was designed with older people in mind, and was without leading questions. Directed questioning is particularly problematic in frailer and older people as they may feel inclined to respond in a manner which they feel is appropriate to the question (Cannell and Kahn 1968). Closed questions may also offer an easy choice rather than the respondent having to answer fully using organisation of recall and personal experience (Smith, 1987). Open-ended questions were used therefore as this allowed older and frailer residents and patients to express their personal views more easily.

The interview schedule covered four main areas – the nursing home/hospital setting; professionals and care; the environment; and feelings about dignity. After the first round of interviews, the researchers decided to make two changes. Firstly, they included an introductory section with two ice breaker questions; how old are you? How long have you been in the home/hospital? Secondly, the section about dignity was moved to the end of the interview as respondents had struggled with this early in the interview and we felt they might be more able to answer later when they had been thinking through the other questions.

The interviews took place over a four month period. In the nursing homes, they took place in the residents' own rooms, and in the hospital setting, either in a private room if this was possible, more often though in the ward environment. This was not ideal, as privacy could not be guaranteed. The length of the interview varied with an average of about 20 minutes. All were tape recorded and transcribed verbatim.

3.6 Data analysis

The researchers listened to the interviews against the transcripts and made any corrections. They also made continuous field notes detailing the different research environments. For example, if a nursing home resident was interviewed in their room, how personalised it was, and the general friendliness of the home.

Analysis took place during and after the interviews over a period of 6 months. Both researchers read all the transcripts and started compiling a content analysis framework. Initially this framework was based on the four main interview sections and each researcher worked on their own version. For example, the first section the researchers analysed was 'dignity'. By putting together all the quotations from the interviews about what constituted dignity, the researchers were able to identify a number of recurring components such as respect, self respect, and mutual respect. As the researchers conducted more interviews they identified more components for example, privacy, being treated as a human being, and pride.

After this first stage, the researchers merged their documents. Regular and frequent meetings, discussion and reflection with the project director who read a sample of transcripts, produced a second level of analysis. For example, within the dignity section, the researchers included a section on how incontinence impacts on dignity which included loss of control and embarrassment. During this on-going process, the researchers added narrative to the groups of quotations and started to subdivide the main areas. Additionally discussions which took place were recorded in the form of analytic notes which were referred to in the final analysis. Developing themes and findings were also discussed and validated at steering and executive group meetings.

The section under the theme 'professional care' was by far the largest. As the analysis developed, the sections became: 'general impressions'; 'communication' including relationships with staff, 'qualities of communication';

'personal care' including time; 'organisational' which incorporated privacy; and the 'environment'.

With discussion and reflection the content analysis framework was reduced by pruning the number of quotations where they duplicated others and increasing the narrative text around them. Choice also merited a distinct section; while still important to dignity, it also reflected slightly broader themes such as gender of carer, participation in activities in nursing homes, wearing own clothes.

The last major theme we identified was 'coping mechanisms' or the ways in which people with continence problems managed when they are in hospital or nursing homes and the methods they use to preserve their dignity and identity. For example, we found that participants used humour to diffuse embarrassment when receiving personal care. Coping strategies could also be sub divided into those which were positive and involved taking some control of the situation, such as self management and others such as acceptance and resignation which seemed to be a more passive way of dealing with it.

4 Findings

This section describes and analyses the findings. It is organised around three main themes with sub-themes from the qualitative interviews. These are summarised as follows;

Defining dignity personal dignity, dignity and other people, dignity and continence.

Management of incontinence: coping strategies

Strategies in the 'outside world', coping strategies in hospitals and nursing homes

Professional care older people and care, communication, personal care, personal care and time, choice and privacy

A commentary is offered at intervals in the sections to provide summary and analysis. Quotes have been used liberally to rationalise the themes and coded to protect the identities of the participants in the study. 'H1' and 'H2' refer to the two hospital settings and 'NH1', 'NH2', 'NH3' and 'NH4' to the nursing homes. Codes are followed by a participant coded number and the page number of the interview transcript for auditability.

We start our analysis with a discussion of what dignity meant to the participants in our study, particularly in relation to incontinence and how they sought to manage it, before focussing on their perceptions of the ways in which incontinence care did or did not maintain their dignity.

4.1 Defining dignity

In our study the participants were older people either in hospital ward settings or resident in nursing homes. When asked about dignity, participants provided a variety of responses that we have divided into two parts, personal dignity or that which comes from within the person and dignity that is a product of interaction with others. In this section we will explore what dignity meant to our participants, firstly in a general sense and then particularly in relation to their continence problems.

4.1.1 Personal Dignity

Dignity appeared to mean different things to different people as this participant explained:

How do you put it, it varies, the other thing is some people might think something undignified and others don't but I am not particular in these sort of ways.....(NH1:3:7)

Maintaining one's dignity was clearly very important:

It means a lot. It means to say a woman is still a woman. I think it's to do with our upbringing – my daughter's, yours, the nurses. We are all setting out to do what we can. I think that's what dignity is but as they say, take my dignity away and I'm finished. I want to grab hold of it. That's what your dignity is. (H1:1:5)

For this participant it was bound up with her sense of identity, status and independence and loss of it would have been devastating. Dignity also seemed to have a quality which was almost tangible, as the above quotation demonstrates, 'wanting to grab hold of it', and for the following participant it was important that she kept it for as long as possible.

Dignity means a lot. To keep your dignity, that's what I've always thought, you know. If I can keep my dignity for as long as possible. Dignity means a lot to me.....Well, self-confidence Pride in yourself and sort of, you know (H2:11:8)

This perception again appeared to be linked to maintaining personal standards and appearances, having pride in one's outward appearance and as well as a more inner sense, i.e. being confident in oneself. Participants also considered privacy as a component of dignity.

Dignity, well, it's being left private. Not being asked too many questions, you know. Just to be private really. (H2:10:7)

Finally, this participant felt that he was entitled to be respected and had earned respect from others both by being elderly and being himself:

Well it means being treated with the respect which I feel I am due with my age or by my personality. (H1:2:p4)

Participants discussed different aspects of dignity. Some focussed on the individual and personal aspects of dignity and saw it in terms of control of personal space, appropriate appearance and sense of personal value. While some of these factors depend on personal action, e.g. dressing oneself, others clearly involved the actions and responses of others and we will discuss this dimension of dignity in the next section.

4.1.2 Dignity and other people

Participants maintained that dignity was also linked to a concern with how others saw and treated them as this was an important factor in their perception of themselves and judgements about their self worth. Central to keeping dignity were relationships with others including contact with and being valued by family and friends were central to keeping dignity. Whilst thinking of what dignity meant to him, a participant who lived in a nursing home remarked:

Well to treat you as a human being rather than just as a job (NH1:3:6)

Although brief, this quotation illustrated the desire for and need to be seen as an individual and equal by the people who were caring for him. Participants spoke of mutual respect between themselves and their carers being a two way process:

I've always been respected. They respect me, I respect them (NH2:1:3)

This mutual respect could form the basis of a 'real' relationship, i.e. go beyond functional interaction to friendship; a relationship based on affect such as mutual liking:

Well I think if you are friendly to them, you get more friendship back, personally.(NH3:1:10)

Thus dignity involved recognition not only of common humanity but also of the uniqueness and special quality of each person:

They don't think you are one of a lot of people that are just not sort of thought of at all. I think they treat you as an individual.(NH4:1:p2)

The individuality is reflected in the view that dignity involves personalisation and personal choice. The following participant felt he was treated with dignity when he was consulted and involved in decision making:

That I am consulted about things concerning myself which I think is important. If they ever do something differently with me they tell me and seek my view of it and I give it and I'm happy about that. I think that's perfectly appropriate.(H1:2:4)

Participants in our study identified two main dimensions of dignity. The first related to a personal characteristic of being a dignified person and involved upbringing, identity, outward appearance and personal pride. The second dimension related to the actions of others, i.e. being treated as a dignified person and being treated as a unique valued human being. The two dimensions were interrelated and while participants wanted to maintain their own sense of dignity and self worth they acknowledged that 'being dignified' was to some degree a performance that was recognised and endorsed by others, i.e. being treated as a 'dignified person'. Furthermore in some circumstances they were not in control of all key aspects and therefore 'being dignified' depended on the actions of others. Since 'being incontinent' can be seen not only as a threat to dignity but also requires the support of others to manage in a dignified manner, it is to these issues we turn in the next section.

4.1.3 Dignity and continence

Incontinence of urine and faeces is a condition which is more prevalent in older people and has physical, social and psychological consequences. Incontinence represents the loss of control of an important bodily function and can be seen as a major threat to 'being dignified' and a challenge to adult status. A 73 year old nursing home resident in our study described the consequences of the sudden onset of incontinence following a stroke:

Oh well, you've lost nearly everything, you know what I mean, you know, you don't like going out far and if somebody comes by and they give a sniffle you think it's you, you know, that sort of thing. You're very conscious of it the whole time. Yes, you certainly are. And you just wonder, do people know? You haven't told them, you know, but you just wonder, do they suss you out, you know? No, I'm very, very conscious of it all the time. Yes, it's worse than having a big lump on your nose or something.(NH1:4:1)

The condition made him self-conscious, and he felt it stigmatised him. Another participant experienced the stigma of incontinence when she went out:

I was walking along here or walking outside and then you'd see this thing dangling between my legs and everybody looking and saying what you got there, what's up with her, like I've got 2 heads. I just ignored it. (H1:1:3)

Many participants talked about the loss of control experienced with incontinence. For example, a 73 year old man had very little time between knowing he needed to use the toilet and actually urinating:

Well, basically, it's - you want to go and you can't hang about. I don't get any warning if I want to spend a penny and I'm sitting here, by the time I have got to that door I have gone. I can't help it you know. It is just one of those things. (NH4:3:2)

A long term incontinence sufferer, an elderly lady explained how she had not been allowed to speak about 'accidents',

Well dignity means to me, self dignity to me means everything in the world, I was brought up very sort of you know, not sheltered but strict we were and at 79 years old, and you didn't mention anything like you've wet your knickers, you know it just wasn't done, do you know what I mean. So dignity to me is all important. (H2:7:5)

She implied that her views on dignity were formed by her upbringing and the current values at that time. In the interview she explained how incontinence had caused her to hide herself away resulting in social isolation.

Our participants seemed to find it easier to explain what constituted loss of dignity for them rather than what would be considered dignified. Providing explanations of concepts through articulating negative discrete experiences has been found elsewhere (Woodhead 2003; Billings and Brown 2006). Having to accept help for intimate care induced feelings of embarrassment and shame and made one participant more aware of her ageing body.

The most embarrassing thing I find, especially when they've got to wash you or they've got to examine your body like, you know. I mean your body at that age deteriorates so badly that you feel like awful, apart from that I don't worry (H1:4:2)

Leaking and bulging pads made other people aware of this very private problem and made the participant feel stupid. Participants also experienced loss of dignity when they had to accept help with intimate care from their adult children:

.....I am a 71 year old man and all my life no one has ever had to help me with my toiletry and suddenly my son had to help me. That was when I lost my dignity. When my son had to do things, personal things for me. (H2:4:4)

One participant felt that simply being incontinent was a cause of indignity in itself:

you've very little self dignity left when you're incontinent, very little, and that is all sort of you know, part of it (H2:7:5)

4.1.4 Comment

As revealed in the literature review, there is a consensus in academic studies that dignity is a difficult concept to define as it is multi-faceted and has different meanings in different contexts. Jacobson's (2007) review of dignity and health differentiates human dignity which is a personal quality or feeling from social dignity which is experienced through interactions with others.

This conceptualisation put forward by Jacobson is relevant to our findings. Our participants had a variety of views of what dignity meant to them. They indicated that personal dignity was central to their sense of identity both in terms of their sense of themselves and also in how others perceived and treated them. Participants also experienced dignity as something which was given by others in the ways in which they related to and treated you. As it was such an important facet of adult functioning, participants viewed loss of or potential loss of dignity as potentially devastating.

Incontinence caused loss of control, stigma and feelings of not being a competent adult and therefore was a major threat to dignity. The vast majority of individuals develop control of their bowels and bladder when they are young children and loss of such control can result in loss of dignity and feelings of not being a competent adult (Miteness and Barker 1995). Thomas

(2001) noted that stigma, i.e. damage to a person's identity, is still attached to incontinence and thus people are unwilling to admit to it and seek help. Horrocks et al (2004) found that older sufferers felt shame and embarrassment about their incontinence which made them reluctant to disclose it and look for professional help. Having to accept personal care meant exposing private parts of the body and having to disclose incontinence which resulted in feelings of shame and embarrassment. Participants in the study developed coping strategies to manage their incontinence.

4.2 Management of incontinence – participants' coping strategies

In this section, we will examine whether participants reported using any strategies internal or external to their environments. Firstly, we consider whether they used them to manage their incontinence in the 'outside' world, and secondly identify those that they use specifically in a hospital or nursing home setting.

4.2.1 Strategies in the 'outside' world

In our study participants spoke of the importance of being able to conceal this potentially stigmatising condition. One participant who was living in a nursing home kept his leg bag from his indwelling catheter covered with a blanket when he went out of his room into 'a public domain' as he worried about the effect on others if they saw it:

Oh I still would (conceal leg bag) because you've no idea who you're going to meet. Suddenly the lift opens and out walks 4 or 5 ladies (who) maybe scream so you can't afford that so once you leave here, that door, you've got to be ... you're in the public domain – that's the way I look at it so you've got to be ready for all eventualities..... I cover it up as much as I can (NH1:4:10)

The same participant kept his incontinence concealed from even his closest family and admitted that this was at some cost to him as he was never able to discuss it with anyone:

Now that's being honest with you, I never discussed it with my sisters at all. And to be quite honest, I have no idea how much they know or how much they don't know or whether they know everything and say nothing, but not a word. Even my best friend; he doesn't know and I have no intention of telling him. So you can imagine how choked up you can be with it, do you know what I mean? (NH1:4:3)

Participants also discussed the importance of being able to conceal equipment which might indicate or provide evidence of incontinence such as pads. Choice of continence aids assumed great significance and being able to wear something which did not show through one's clothes was important. However, although the smaller and less obvious incontinence pads were preferable they were unfortunately not so absorbent and this could have undesirable consequences for this participant:

It's these rotten pads that I don't like. It's like you've got a bundle underneath your bottom. That's what loses your dignity when you have to wear those things. They have got small ones but they are no good, they don't soak up the water. You feel such a dope when you wet yourself, it comes through, oh, horrible. (NH3:3:6)

When participants could hide their incontinence they felt 'normal' and less stigmatised but such strategies had emotional and practical consequences. Not being able to share difficulties and experiences with family and friends can result in loss of relationships and isolation.

Other participants appeared to have accepted their incontinence and resigned themselves to its consequences:

You just get on with it luv, you can't do anything about it, there is nothing else they can do for you. I mean they could probably put a catheter in some people but I don't want that. I'd sooner have the pads. (NH3:3:7)

I don't find any great problem there because as I say, you get to know the people and you take it as routine now – there's nothing I can do about it. I've got to live with it and all the rest of it and get on with it (NH1:4:5)

Revealing and adjusting to incontinence seemed to be a process that took time and participants who had gone through this process indicated that over time their initial embarrassment faded.

I used to, I used to be very embarrassed at one time and shy and all but I sort of got over it. (H2:8:4)

Chochinov et al (2002b) in their study of terminally ill people and dignity maintained that acceptance is part of an internal process of adjustment to changing circumstances which help to maintain dignity. Concealment, acceptance of and resignation to incontinence were coping strategies employed by a number of our participants to manage their condition, others chose different methods, such as comparing themselves to others with the same problems and thereby normalising it:

The only thing is you look around and you see the rest and you say, 'Oh well, we're all in the same boat' more or less. (NH1:4:8)

4.2.2 Coping strategies in hospitals and nursing homes

In our study, participants were all living temporarily or permanently in institutions (hospitals or nursing homes) and therefore had to adapt their general strategies for managing incontinence to the specific demands of living in such settings. Some participants reported using pro active strategies such as self management or taking control of the situation. One woman in our study reported how she minimised the risk of wetting the bed by padding herself up before she went to bed.

it's very difficult when you know that every time you get into bed, because I think that eventually, you're going to wet the bed.... I always wet the bed, I know that I'm going to wet the bed, and so I'm always padded up for that. (H2:7:2)

Others, such as this 73 year old lady, managed by a self imposed toileting regime:

I've tried to get to where I can go about every 3 hours but usually if I go... and I do wear pads. I do wear pads, but I usually find that they're damp when I get there, and on the odd occasion when they're nice and dry I'm feel like clapping my hands because I'm dry.(H2:14:1)

Self management of incontinence, such as getting padded up or regular toileting regimes, helped people to maintain their dignity and in the latter case gave the participant a sense of achievement. This participant described how she made preparations for visitors by ensuring that no signs of her incontinence were visible:

It's like outside people coming to visit you and all that, making sure that they don't see anything, smell anything, notice anything and I suppose we all want to go out of this premises with a bit of pride I suppose. That's how I see it anyway. (NH1:4:2)

Another coping strategy used by a number of interviewees was deflecting embarrassment with the use of humour. An 83 year old nursing home resident in our study lightened situations by using humour and laughter:

You can take it with a pinch of salt you know because as I say you have a good laugh, you make it funny, I do anyway.... The chief nurse says to me "don't you ever lose your sense of humour".I tease them something rotten, I'm afraid. (NH3:3:6)

Interestingly, humour was something which was both used by participants and appreciated as a quality in their carers. McCabe (2004) suggested that the patients in her study appreciated the nurses' humour and the two-way banter which went on increased participants' self-esteem. Participants related how they were 'teased' by carers, but in the context of a caring and friendly relationship:

Some keep you waiting a long while, they tease me now and again, you know. Others say they'll be back in a moment and I say, 'Where are you going, Heathrow?', They're alright ... (NH2:1:6)

If everything else failed, then participants reported that they apologised to nurses or carers providing their personal care:

I am apologising to them all the time. If you know what I mean? ... Well I wouldn't ask anyone to wipe my bum. But they do. For a 71 year old man I've got a little bit of dignity. But I can't help it, it's got to be done so hence I apologise to them. (H2:4:2)

4.2.3 Comment

Research studies have found that people develop their own personal strategies for coping with incontinence which enables them to take some personal control over the situation. Mitness and Barker (1995) divide such strategies into three categories planning ahead, improving physiological control and environmental control. In a study of women and incontinence, Diokno et al (2004) also identified three major groups of strategies: defensive, concealing or hiding urinary incontinence and treatment.

There is resonance here to our findings. Coping strategies helped people with continence problems to take a degree of control over their situation by either enabling them to take active control or if they could not deal with the consequences of 'accidents', resign themselves to loss of dignity through acceptance. They developed strategies for use in the public domain, such as planning ahead and concealment. It was far harder for people to maintain their usual levels of control over their circumstances when they were either admitted to hospital or nursing home care. Matiti and Trorey (2004), in their study of perceptual adjustments, suggested that when people were admitted to hospital they underwent a process of weighing up potential loss of dignity against the health benefits and value to life. This balancing out allowed them to suspend their normal values and submit themselves to procedures which they would otherwise consider a threat to their dignity. Hospital admission is however, a temporary episode in a person's life and thus patients could readjust their perceptions of dignity after discharge.

Admission to a nursing home is usually a far more permanent arrangement and little is known about how residents cope in such circumstances. In our study, residents appeared to be resigned to a situation they did not necessarily feel was the best for them in order to maintain their dignity. However, in both settings, both participants and their carers employed the use of humour and banter to diffuse potentially embarrassing situations or used normal social conventions such as apologising for the extra work they had created. In the next section we explore further participants' views on the professional care they received and how this impacted on their dignity.

4.3 Professional care

Professional care issues was a major theme of our findings, and important in enabling clear links to be made between dignity and facets of care. Following a section that describes how older people shape and articulate their experiences of care, themes relating to communication, personal care and choice are analysed in detail.

4.3.1 Older people and care

The National Service Framework for Older People, Standard Two (DH, 2001) aims to ensure that older people are treated as individuals and enabled to make choices for their own care. The participants in our study were all older people and a number of them were frail and unable to live independently. The main themes which emerged in relation to their care were communication, personal care and time. Participants generally spoke highly of the standard of care in their own settings, in fact, in our study nearly all participants started by making general positive comments about their care. Such positive responses by older people have been well documented in the research literature. For example, Beel-Bates et al (2007) in a US study of elderly people living in assisted living suggested that participants used participation, pleasantness and cooperation, and gratitude as methods of showing deference in social exchanges. The researchers maintained that in relation to staff, use of deference enabled residents some degree of reciprocation. The majority of participants in our study repeatedly expressed positives and discussed how well nurses and carers treated them, their experience of care in general was mainly positive.

They are very kind and very nice to me I have got no complaints whatsoever. (NH4:3:3)

I don't think they can do anymore than what they are doing.(NH1:5:6)

While initial responses were positive, some participants qualified these comments with caveats which indicated specific concerns. In particular they noted their experience was varied according to which particular individuals provided their care. Some staff were more caring and had more time than others. There were many examples of this type of response from nursing home residents.

Oh it is a nice home. It is well run and anybody that would fault it would be very hard to please. It is a good home and the nurses are very nice. Some of the carers are...you know. But you get that in every walk of life you do. (NH2:2:2)

They're all easy going. They're all ... oh yes, there's no ... we certainly have no rough and gruff people here at all. (NH1:4:6)

In the first quotation below, the participant makes the point that the staff nurses, although good are not as friendly as the carers and he explains that this is because of work pressure:

the staff nurses, they're very good too. They're not quite as friendly some of them, but it's not out of disrespect it's out of what they're doing and they've got their mind on what they're doing (H2:14:3)

Hospital patients also made allowances for perceived lapses in care:

I know that they're very busy and they can't attend to everybody at once. (H2:6:4)

It was interesting how participants attenuated negative comments by wrapping any criticism around 'positive brackets', emphasising that no blame should be attached, and that any problems were due to special circumstances beyond the control of the staff.

Having established the mainly positive views of older people to those who care for them, the remainder of this part of the report explores the themes identified by participants as important in maintaining their sense of themselves.

4.3.2 Communication

Communication with others, whether verbal or non verbal, is essential to make people feel they are being listened to and understood and taken seriously as an individual in their own right. In settings where vulnerable and possibly frail older people are being cared for, the importance of good and effective communication is paramount. McCabe's (2004) person-centred study of nurse-patient communication identified lack of communication as a major theme and noted that patient centred communication involved and encouraged patients to negotiate and to be part of decision making in their own care. McCabe contrasted patient-centred communication with task-centred communication which concentrated on the administrative and functional activities only and did not encourage the development of the nurse-patient relationship.

In this section, after briefly examining the views of residents and patients on their relationships with staff in the nursing home and hospital settings, we look more at those aspects of communication that participants felt were necessary in making them feel respected and dignified.

(i) Relationships with staff

Family support, relationships and social contacts all contributed to participants' sense of personal identity and dignity as described in the first section. In this section we examine what nursing home residents and hospital patients said about their relationships with staff. Nursing home residents commented on the importance of getting to know staff even when there were frequent staff changes and of getting used to such changes.

But there's so many different changes, they come and go but the ones I've grown accustomed to, they treat me well in that respect (NH1:3:6)

You get used to the faces and call them by their Christian name. In the beginning it was all strange and 'Different one again' today. Another different one' and then I discovered well you go through the complete system and that's fine. You don't take no notice of it in the end. (NH1:4:4)

On the whole, residents were able to acclimatise themselves to change. However, one resident with visual impairment found it difficult to identify new staff as he had to rely on recognising voices.

I have to try my best to recognise them but it is not that easy especially at my age, I'm getting on a bit now but I do try, do try, a few I recognise straight away like the one that has just walked in, Jane, I recognise her voice. (NH2:1:6)

Participants emphasised the importance of being greeted with a smile by staff:

Oh yes. She's always smiling. First thing in the morning she's smiling – how she does it, I don't know, but she is.... . (NH1:4:6)

The young ones are alright. The young nurses They smile. You smile, they smile back at you. (NH2:4:11)

The comments were mainly positive and a resident at one home remarked on knowing and having developed a relationship with the kitchen staff:

They are very good actually. The cooks, the chefs, must not call them cooks, chefs are very good (laughs). They know you all by name and do as much as they possibly can to help (NH3:3:5)

A number of the hospital patients reported being addressed by their chosen name or title, mostly preferring their first name. The participants indicated that they were given a choice over the way in which they were addressed and how use of preferred title could improve the way they felt.

Oh yes, they're excellent, they ask you would you rather be called Mrs or by my first name, but to me it's most friendly to say Doris, you know than Mrs, I don't mind once being called Mrs, I just say Doris, but they speak to you alright. (H2:5:3)

Always call me Queenie, don't want Mrs this or Mrs that! It makes me feel better (H1:1:2)

Although there were frequent staff changes, participants in the study valued the relationships they created with staff, being greeted with a smile and being addressed by their preferred name or title. In the next section we will discuss the qualities of communication that added to or detracted from participants' views of themselves.

(ii) Qualities of communication

The findings indicated that hospital patients were particularly fulsome in their praise of the nursing staff. When discussing the qualities they valued in staff, they described a combination of verbal and non-verbal communication skills which combined to provide a friendly and enabling atmosphere. Such an environment, where they felt respected, listened to and talked to as individuals, added to their feelings of dignity. This was especially important for our participants as they were more vulnerable because of their incontinence.

You can feel the respect when they speak to you. You know you can also see it, you can feel it. (H2:2:4)

I have no problem with that, they're all very respectful. Lovely, they all are, right down to the Matron and the, who's after the Matron?Well whoever she is, she is the boss of everything. She's lovely, she'll sit and talk and she did ask me if there is anything that I had a complaint about. (H2:14:2)

One participant gave examples of the types of conversation that she had with the nurses which added to her feeling involved and to her sense of belonging and identity.

... 'have you seen what kind of day it is', 'gosh it's cold outside'. All that kind of thing you know and 'did you hear from your children', and you know, 'how many children have you got' and you know and all this kind of stuff. Inane stuff that they know is important to the patient, not important to them, but it is important to the patient to keep their minds going with what's going on in their own lives. (H2:14:4)

The content of the communication appeared 'inane' but was important in stimulating to patient to feel part of things and to reassure her that she was perceived as a person. Patients also commented on the importance of tone of voice and the sense of security it gave them when it was empathetic:

they don't shout at you. They all speak just ordinary; not too loud, not too soft. And they all love my accent. (H2:11:6)

I think a kind voice is the best thing of all, it makes you feel safe, you know and a hard voice is very very hard to take, especially if you're under the weather and everything. (H2:12:5)

Participants also commented on the courteous and respectful manner in which the nurses approached them.

it is the kind way you are approached. It is not in a grumpy way or a sort of what do you want now way it is a kindness, what can we do, how can we help you.... Well quite honestly this is all just general the general approach to you it is courteous, kind, it is never in any way disrespectful. (H2:2:3)

A number of patients commented on feeling they were treated as an individual which increased feelings of self worth.

You know, it's not like 'Them in that ward', you know, that sort of thing – it's not that. If there's anything they want to talk to you about or anything like that, she'll come and ask me properly, you know. (H2:11:3)

One of the major themes that emerged from the interviews with hospital patients was the importance of reassurance that nurses gave. Patients were often feeling depressed, embarrassed, and extremely conscious of being incontinent and there were numerous examples of positive care and more importantly, reassurance from nurses to patients. These so called 'soft skills' were very important to patients, particularly those who were feeling vulnerable. The next two quotations demonstrate how important sensitive care and reassurance were for patients during episodes of incontinence.

Well, it's nice to know that people care for a start and the staff have been very kind here you know, sister the other day I said I was afraid I'd had an accident in bed you know, she said 'don't worry about it, don't worry about it at all'. I think that's why she came and asked me today because I'm so particular, I didn't want to, you know, cause any problems but no they're always very kind actually and no problem getting up in the night you know, you only have to buzz the buzzer. (H2:6:2)

I don't know for any ward but at this ward they're very good because I'd pee'd myself, no because I lost control of the muscles and I wet myself on the wheelchair because I was asking for a bearer but by the time they come I'd wet myself and I said 'oh I've wet myself', you know I was very embarrassed because I'm not ..., and they said 'don't worry, don't worry' and they pushed me in here and they drew the screen and they fixed me up, you know and I felt alright, they respect you. (H2:5:2)

The qualities of communication which participants appreciated increased their sense of belonging and thus helped in maintaining their identity and dignity.

(iii) Less helpful aspects of communication

A number of participants felt the way in which they were spoken to did not add to their feelings of self worth and dignity and when this occurred they felt child-like, disrespected and disgruntled. One hospital patient reflected on the tone of voice the nurses sometimes used and how this made her feel:

Sometimes it is, sometimes it's very hard voice, you know, very strict, and I tell 'em they use you as if you're a child (H1:3:5)

A minority of the nursing home residents were unhappy about the tone of voice in which they were addressed and others that they did not feel as if they were spoken to at all.

they don't talk ...they smile at you.. but that's all. They don't talk to you. ..Well one word, two of them, ...that's all now isn't it. They don't really talk or anything like that. Just sit down here and look at the wall or the television. (NH2:2:18)

This participant experienced a lack of respect in the way he was spoken to at times which affected his mood.

Yes on the whole, I think on the whole they come through and they say "Good Morning, how are you?." I say, "not so bad thank you". "Are you in a moaning mood?" "Yes, yes I am" "oh dear". Because you see it largely depends on what you call moaning. If I breathe deeplyPhew!!... do that. They say that's moaning.... it makes me feel irritable because I know that I am not moaning. I mean my voice changes if I moan. If I started to moan to you, you would know I was moaning. (NH3:1:6)

Linking to previous sections, the issue of 'making allowances' was evident again here. One resident explained how he did his best to understand the nurses and make allowances for them because of the nature of their job:

I'm a man of understanding. How do we know when these nurses go home, some are married some are single, they can have a row and of course, when they come and do their work, and if you don't realise that, you can't be human, they've had a row at home, now they've got to come and do this bloody work and things, you've got to understand. I don't know, it's not a nice job (NH1:1:5)

In this section we have identified a number of facets of communication, such as tone of voice, friendliness, chatting, being approachable, showing respect, reassurance that go together to enable effective communication and empathy. Such communication enhanced self-esteem and a sense of belonging. Where communication was not so helpful, participants said this increased their sense of isolation and added to feelings of not being seen as an individual.

(iv) Barriers to effective communication

There were a number of barriers to effective communication which impacted upon participants' abilities to establish and develop relationships. Verbal communication with staff was sometimes difficult for participants because of their own communication problems such as deafness or visual impairment. In a European study of dignity and communication with older people, Woolhead et al (2006) noted that although professionals acknowledged the importance of spectacles and hearing aids in communication with patients, they frequently forgot to invite older people to wear them. One elderly lady in our study had very poor hearing and felt that it impeded her communication with the nurses and other patients.

Yeh, 'cause I can't hear very good, I can only hear a bit out of that ear, and that one I can't hear. I've got two hearing aids but they both don't work.... I can't make conversation with people, when you can't hear what they're saying and as the nurses when they say anything and I ask them to repeat, sometimes they'll repeat it, sometimes they won't, so I always say 'you don't want me to hear what you've said'. (H1:3:2)

This difficulty in communication raised the potential for misunderstanding between the patient and nurses and isolation for the patient. Language barriers between care staff and service users were identified as an issue in a recent 'Dignity in Care' survey (DH 2006b). Many of the staff in our study had a strongly regional accent or English was their second language, particularly in the London hospital and nursing homes. A minority of participants struggled to understand either their accents or the way some staff expressed themselves. This participant had very little sight and described his experience of trying communicate with staff from different ethnic backgrounds:

Sometimes they are a little bit (difficult to understand), not being racist, but some of them come from Africa and they're not so fluent as they are from the Caribbean and also India and they are very good, very good. But those from Nigeria and places like that, I can't understand, they've not been here very long, that's the thing. It takes a long time to learn. (NH2:1:6)

Some of them are a bit ... Some of the foreign accents, do you know what I mean? I manage to understand them, you know. (H2:9:3)

Occasionally, as this participant noted, carers and residents struggled to understand each other:

There are only a few people that I can't understand what they are saying and I don't think they can understand me. (NH3:2:3)

However, when the relationship is positive and there is a good rapport between the nurse and resident, communication can be a negotiated process and this does not have to be an insurmountable problem:

There's a young nurse, I don't know if she's Japanese or what but she's the kindest person and she's a good nurse. You just have to ... but she comes to me and she takes her time and then she says to me 'Did you get that?' and I think 'Well no, not really' so she starts telling me again. (H2:11:6)

Occasionally participants felt they had been given incomplete information or that they had difficulty in understanding the technical terms used to explain aspects of their treatment such as medication.

I don't understand their jargon, you know. I mean I'm always on pills, but I don't know what, you know, the names they give them and that. But you know, I might say ... I'm always asking, 'What's that? What's that for?' and they tell me but in their own jargon, you know. (H2:10:4)

Or that they were given insufficient information about their progress and discharge as this participant explained

No, no one says anything, I was going to ask the lady that goes around and sees these people like and have a word with her to just get an inkling or little satisfaction to know that I am going home or when I am going home but you know they keep saying oh I'm going home but they don't tell me when and then of course there the same as me but it like holiday you can get fed up with it. (laughs) (H2:8: 5)

Very occasionally just responding kindly and gently to the patient's needs but without speaking seemed to be what the patient needed. In this example, a 78 year old woman had developed incontinence after having surgery and following the removal of an indwelling catheter. She became very depressed in hospital but describes how a nurse intuitively knew what she needed.

I wanted to end it all and the funny thing was and I shall never forget this, I just, when they said you know 'are you getting up' I just turned my face away, I just hid my face and I never spoke. Nothing at all, and I heard all the breakfast doing and the beds being made and then a nurse came in and said 'oh Mrs X I've come to take you for a shower'. I thought I don't want a shower, I want to die. You know I was very down and she took me into the shower room and she washed my hair, washed me very gently, she never spoke and I never spoke and yet she was kindness herself and she dried me gently you know, and she took me back, talced me down, and I don't know it just... I said to her before I left, I said that I shall never forget that day because I had really reached the bottom, and I said 'you never spoke to me and she said 'no' (H2:12:6)

4.3.3 Comment

There have been a number of research studies which have examined communication between older people and health professionals. Caris-Verhallen et als (1999) observational study of communication between nurses and older people in two settings, a home care organisation and a nursing home, used five categories of verbal communication: social; affective; structured; about nursing and health; about life-style and feelings. The researchers found that nurses with higher levels of education tended to use less social communication than carers and more structured and health related communication. McCabe (2004) identified empathetic communication as important in helping older people to understand and cope with their illnesses and emphasised the positive influences it can have. She also found that older patients appreciated nurses' friendliness and humour and that such behaviour was interactive and reciprocal improving patients self-esteem. Other studies have examined non verbal communication. Non verbal communication, for

example touch, can be particularly important in the care of older people as many have impairments such as poor sight, hearing or communication difficulties. In their observational study of non-verbal communication between nurses and older hospital patients, Oliver and Redfern (1991) found that despite the importance of touch, most was instrumental or task oriented rather than expressive.

In our study, while some connections to the wider literature can be made, it was clear that dignified communication is a two way process in which both parties respect and listen to each other. Hospital patients and nursing home residents valued such communication, particularly if it was given in a relaxed and friendly manner. Participants identified a number of qualities which they felt added up to such communication where they felt listened to and valued. They also noted a number of barriers to successful communication which could result in loss of dignity and a sense of isolation. This included aspects such as dialect and accent, the use of jargon and their own sensory impairments that were not fully taken account of by staff. In the next section we explore the participants comments on personal care, examining the qualities they feel contribute to dignified care and those which detract.

4.3.4 Personal Care

This section incorporates the actions involved in the caring process, such as bathing and toileting plus the qualities of caring that participants thought were important. It overlaps with the previous section as verbal and nonverbal communication takes place during care episodes. The section is divided up into two parts, the qualities which participants appreciated in carers and nurses, particularly in relation to their continence care, and what they found difficult.

(i) Qualities of caring

Participants appreciated staff whose approach was friendly, kind and helpful. In the following quotation, the participant listed a number of activities of care which he felt contributed to 'good' care:

All the staff are very good. All of them. If you want to know anything they do their best to try and help you. Things are sorted out....: Oh yes, they always say don't worry. Very nice. Don't get shouted at or nothing.
(H1:1:1)

Staff responded to his requests for information by finding and sorting things out but did so in a helpful and reassuring manner. A hospital patient who acknowledged herself as being anxious, commended staff for being, 'patient with my impatience; (H2:2:6) as it made her feel she was being seen as an individual. Participants, such as this nursing home resident, appreciated staff that were energetic and non complaining:

Well she's always bubbly, she's pleasant, she never complains, nothing is too much: 'Oh, I'll get your water now for you. It's pretty low – I'll get you a fresh one'. She's always energetic, you know and all that, which is great. (NH1:4:7)

Older people often feel that they are a 'burden' and that the job of looking after them is unpleasant, but when care is delivered in a willing and thoughtful way such feelings are reduced. Woolhead et al (2004) noted that the fear of being a burden on both society and their family was a major dignity issue for older people. When being given personal care and handled participants valued gentleness, thoughtfulness and touch:

They've washed me and take care of me and they've done it with gentleness and kindness and chat. (H2:14:4)

I don't know, it's all the same, I mean they're all very, they're all very thoughtful about how you are and what your problem is and they just seem to know how to treat you and how to touch you and everything. I don't know how to explain it other than that.(H2:14:3)

Interestingly, when participants commented on their personal care they often listed a number of components encompassing verbal and non verbal communication and actions which combined to make a satisfactory encounter for them.

In relation to continence care the majority of participants commented positively, but one participant who had suffered from incontinence for most of her life, and had experienced many hospital admissions, remarked:

I'm always having bad experiences in incontinence care, because incontinence is a hell of a thing. Especially when you've had it as long as I have, it's just a hell of a thing to have to live with it. Most of them are very good, in fact 98% of all nurses are excellent when it comes to care for the incontinent, but as I say, for a lot of them you see it's an extra duty and it puts the pressure on, but they manage, they manage. (H2:7:4)

However, most participants felt their care was sensitively handled and consideration given to their privacy:

If you ... previously, I mean, say if you need the commode or anything like that then the curtains are always drawn and nobody ... only the nurse could just peep through and say, 'Are you all right Mrs B?' and I'd say, 'Yes'. 'Well if you need any help just ring this' (H2:11:2)

Participants varied in the way they managed their incontinence. Consequently being treated as an individual and nurses or carers being aware of such needs was important in maintaining their dignity. This patient commented on her desire for efficiency regarding her supply of pads when in hospital but also discretion and privacy from staff.

They know that I wear them but they don't make a big deal out of it. It is not a big matter of fact thing. If I ask them for a pad out of the drawer, oh yes certainly, they get it; they give to me, finished. They don't question, don't talk about it or anything after that unless I want to and that's how it is.(H2:1:9)

In addition to discretion, participants wished for promptness and efficiency in dealing with episodes of incontinence (this will be discussed in greater detail in the section on time). Participants wanted to be cleaned up quickly and it was important for them that the staff knew their individual needs and were responsive to them:

They know that you can't help it, they know that you're going to wet the bed or worse, they know they've got to come in when the bell goes and clean it off, whatever time day or night. They just do it, bless them, they're very very good, they really are. (H2:7:7)

Being kept clean and feeling the environment was hygienic was also important and this participant commented on the pleasure that having clean bedding everyday gave her:

I think it's wonderful, I mean they change the bed, every bit of the bedclothes once a day, sheets, pillowcases, all changed every day. You can imagine that can't you, you can never do that at home. (H1:4:7)

Most of the comments about personal care were positive and complimentary, but a small number of participants from all the settings had negative views. The majority of older people do not want to make a nuisance of themselves in hospital and residential settings and be seen as demanding. (Stockwell, 1972). After buzzing to use the toilet and being forgotten, this participant had to choose between buzzing again or wetting herself.

Sometimes they forget all about you. They forget all about you sometimes. They answer the bell and then they say, "I won't be a minute, I'm just going to so and so", and then they go off to somebody else and forget you and you have to start pressing it again or do it in your drawers. .. (NH3:3:1).

The situation created a dilemma in which she had to balance the risk of appearing demanding by buzzing again against the consequences of wetting herself and having to be changed and cleaned up. Older people are often frail and suffer from multiple health problems and the way in which they are handled and moved around can cause pain. One participant suffered from a painful degenerative disease and commented that the staff pushed her wheelchair as if it was a bulldozer:

I think it should be a little bit more caring and watch what where they are going when they are driving you in and out of the toilet there, you know.(NH2:2:4)

It is the pulling about you know if you've got aches and pains, you know. It's rolling you over and you know, and straining on the leg. It's something you have got to put up with I suppose, I don't know. (NH4:2:7)

Being seen as an individual and treated as a human being is essential if dignified care is to be delivered and a minority of participants felt that this was not their experience. One participant felt as if she was not handled gently and this made her feel dehumanised.

...sometimes the nurses are very very cruel, I think very cruel the way they handle you, they don't think of you as a person, I told them that they think I'm a sack of potatoes, especially when they're going to put me, to help me going to bed. (H1:3:2)

A second participant spoke at length about her experience of using a commode at night and the unhelpfulness of a night nurse. She explained that care was not person centred as the nurse had not taken the time to understand what was important in helping her get out of bed and how difficult this was for her. The nurse's impatience made her dread asking for help and to feel like a nuisance when she did ask for the commode.

There's a little nurse, she wasn't in last night. Me, I'm not awkward but if I have to I use the commode and she's not sort of helpful, I have a job because my legs are so heavy, I can't get them off the bed onto the floor so I have to ask, and then I have to ask to put my shoes on. Everything and I think they should know how important this is because you're gonna be doing this in the dark, then I have to have my wheeler brought round for me to get up to get on the commode. If they're a little bit impatient then that really begins to worry you, I know I'm a bother you know, but most of them are told that, I don't think that she got trained here but I don't know but you know, I dread her coming in if I should need to go. So, it's all this sort of thing that it worries us and I don't think there's any other as far as I'm concerned, but to have someone who hasn't learnt up before they get what the person needs, it's worrying. (H2:12:3)

Participants strove to qualify their answers by providing a reason why the care was not ideal and this participant took some of the responsibility on herself for being unpredictable in her movement.

Yes, they're not sort of .. I mean obviously sometimes you think 'gawd, you know mind how you go', they pick you and you think 'oh my god', but I mean there's no meaning in that, there's no malice in it. Either they're a little bit pushed or perhaps you know, you're not quite as responsive as they expect you to be. (H2:7:4)

4.3.5 Comment

The manner in which personal care is given contributes to or detracts from a person's sense of dignity. Irurita's (1999) study which explored the factors affecting the quality of nursing care from the patients' perspective, identified four levels of care; *soft hand care* was the highest level which included the personal touch and demonstrated empathy; *firm hand care* was functional and adequate but without the extras; *hard hand care* was technically incompetent, minimal, functional and off-hand; *rough-hand care* was poor and made patients feel like objects. In our study participants comments were mainly positive and reflected elements of person centred care but sometimes people felt care was lacking.

Generally participants were very satisfied with the personal care they received both in hospital and in the nursing homes. They valued qualities in their carers which made them feel like human beings and individuals. When care was less satisfactory, they tried to reduce blame by providing excuses or even taking some responsibility on themselves. However, it is clear that when individuals are handled roughly, or treated with impatience, it impacts on the way they perceive themselves and causes a loss of dignity. In the next section, we report on and examine time issues in the delivery of personal care.

4.3.6 Personal care and time

In this section, participants identified a number of different time-related issues, including, the length of time they had to wait for care, whether they felt rushed in the delivery of care, the length of time it took to give personal care. In this section, we will explore the issues raised and how they impacted on the participants feelings of dignity. We start with a number of responses to their requests to use the toilet and move on to how time impacts on the delivery of care.

(i) The need for rapid response

Earlier in the report we discussed how participants identified the loss of control involved in incontinence and when in hospital or a care home they were reliant on others. It was therefore important for participants that when they needed help with toileting such help was readily available; waiting was not an option. Participants considered the call bell or buzzer an important way of summoning assistance:

...they came to you as soon as they could, when you ring the bell. In here, they just come as soon as you ring the bell and you're finished and that's it, they're prompt. (H2:14:2)

If I want to go to the loo, no problem they are with you in a minute and at night time, you see that red wire. Well in bed if you want someone, press it and somebody comes" (NH1:5:2)

There were, however, mixed views on promptness of response of staff to their toileting needs, particularly from the nursing home residents. As before, residents tried to deflect any blame from the staff, but the end result was a loss of dignity for this participant who resorted to shouting when she needed attention:

It's not very quick action. Not the girls fault, they are busy doing something else and they can't get there quick enough and often you have accidents. It is not very nice and you have to scream and shout and tell them you are doing it in your drawers and your running out of time and as I say it isn't always their fault. (NH3:3:1)

Participants in both hospital and residential homes felt that staff shortages caused delays in delivering care. An 83 year old woman described how the length of time it took for staff to attend to her particularly at night caused her anxiety:

I think my biggest complaint, if it is a complaint and it's not their fault, they're so short of staff at times. As you heard the buzzer going, sometimes the buzzer goes and goes and goes for a commode and you have to wait quite a long while, and that can be a little bit daunting....., but if you really want to go, you know... It's probably only minutes in reality but you know it's the same in the night and then when there are perhaps 2 people on, and there's 29 people that they've got to look after and some are very very poorly and need a lot of help.... but that is, that's my biggest whastit you know, not worry but you know.(H2:13:2)

Later in her interview she provided an insight into how endless time can feel when you are a patient sitting behind the curtains waiting to get off a commode:

.....but as I say when you're sitting here and I haven't got a watch, and perhaps that curtain is pulled so I have no idea of the time, probably only about 3 minutes but it seems about 3 hours.(H2:13:5)

Another participant understood that the routine of the nursing home, in this case staff handovers, took precedence over her need to use the toilet:

Yes, I hold it for a long while. They can't come at certain times coz they have got changeover, they have to have a meeting you know – the changeover and you've got to wait, you can't go and that's it and then its too late and accidents happen. You try not to but you can't always hang on. ...(NH3:3:7).

Having to wait for help to get on and off the toilet whatever the cause impacted on participants' ability to maintain their dignity.

(ii) Having enough time and not being hurried

Participants from both settings identified staff shortages as an impediment to getting care when they needed it. It also meant that personal care, when it was given often felt rushed and fitted around the staff schedule:

quarter past eight, that'd be about the latest and they want you to be dressed then and everything done for half past to go up to the dining room but you can't do that..... Well she dresses me and everything but it is a rush job, you know what I mean?..... Quarter past eight and get you, you know, out of bed at five past eight. (NH2:2:2)

In this instance, the participant had to get washed and dressed to get up to the dining room for breakfast. One participant wittily recounted a nurse's robust approach to giving personal care but also explained that he preferred the carers who took longer:

We have one girl, , and she's 'crash, bang, wallop' – 55 to 60 seconds and we've one or two others that prolong it, say quarter of an hour.....Well I think the quarter of an hour one is the best because everything is done in detail rather than the crash, bang wallop, you know. (NH1:4:3)

However in continence care, some participants emphasised the importance of speed so that any potential embarrassment could be minimised. The following participant preferred continence care to be efficient and quick:

No, no, no, no, as long as you don't take long, as long as they're not an hour or two hours at it.....They do do it quickly. (NH1:1:5)

4.3.7 Comment

When in institutional care, patients or residents are subject to the routine or shift work patterns of that organisation. Getting up, mealtimes, getting washed and going to the toilet are all activities which are determined according to the time of day, levels of staff and what is happening. For example, in a hospital ward, if there is a ward round this will have an impact on the way the nurses organise the care. In relation to incontinence, this is often managed by toileting or checking individuals every two hours, rather than responding to an individual's needs. In a recent report on care homes at night Kerr et al (2008) noted that many residents are checked two hourly throughout the night, a practice which was not effective in continence management and caused sleep disturbance. Processing of care into bulk units, such as everyone being checked and or toileted before meals, results in a structured busy time for staff and consequently a potentially difficult time for those in their care who feel rushed or cannot perform at the designated time.

Time emerged as a major theme for our participants. They needed to be attended to promptly to prevent accidents or to minimise them and felt anxious when they were unable to obtain such a response. Sometimes they felt rushed when receiving care but were always willing to find a reason why care fell short of what they needed, even when it seemed as if the routine of the institution was being put above their individual need for care. In the delivery of person centred care, individual's needs should be put first allowing them choice over their care which in turn empowers them and allows them a degree of control. In the next section we report on the participants views on choice in care.

4.3.8 Choice

Being autonomous and able to exercise choice over decisions increases older people's feelings of inclusion and self worth. (DH 2005). Woolhead et al (2006) stressed the importance of respecting older people's choices when in care, such as whether to have a bath or a shower and the gender of their carer and the positive impact this could have on their dignity.

In our study participants varied in their attitudes towards choice about personal care. As with Maiti and Trovey's (2004), participants who adjusted their perceptions of dignity whilst being in hospital, one participant when asked about choice commented:

To a large extent I don't look for choices because I am in hospital and I am here to be made well. I accept that there are some things that have to be borne that I wouldn't like to put up with otherwise.I have to obey the rules of course and I don't obey rules at home particularly. That's all I think. There is nothing difficult about life here for me. (H1:2:3)

He acknowledged that there were indignities he would have to endure as a hospital patient but it was worth it for his good health. Other participants expressed similar views specifically in relation to their continence problems.

(i) Choice in continence care

Although choice is a dominant theme in a range of policy and practice documents, participants in our study did not always feel that choice was an appropriate or relevant option in relation to their continence care:

No, no, they don't give me a choice because the fact is, it's got to be done, whether I want a choice or not, it's for my own benefit, it's not for your benefit, it's not for their benefit. (NH1:1:6)

The concept of choice in continence care did not seem important to the following participant, as he wished to be changed and he was the only person who would benefit from this.

You know what's going to happen because they do the same thing each time so that's it..... Well, I don't need any choice, what they do is necessary, that's it, I can't say, well I wouldn't say "sorry go away I don't want to know you" so that's it. I just accept it. (NH4:1:6)

Continence care in the nursing homes in our study tended to be carried out in bulk, for example, everyone was toileted before meals. This system of care effectively reduced or removed choice for residents as staff generally appeared under pressure to get through the work in time. Lack of choice ensured the routine was maintained, things were predictable and participants learned acceptance of the situation and did not question if things could be done differently. Routine and consistency appeared to give one resident a sense of security when it came to getting up in the morning:

First thing in the morning when they come to get you up at 6 o'clock you have a commode, straight on to the commode, so not too bad at all. Well they always ask if you want it. If you don't want it, then you don't have it. Then I always want to go by the time I get to the morning. (NH3:3:2)

However, the same participant explained that there were times, for example in the evening, when she was put on the commode for long periods which was very uncomfortable for her.

Before lunch or afterwards,...they ..put you on the commode and then they go off to someone else and leave you on it and it nearly kills you...Very impersonal and catches your bottom and everything, it is really horrible. If they would take you off the commode directly you have done it and put you in your chair I would be a lot happier but they don't, they get off and do something else, always in the evening. (NH3:3:1)

And that there were times, such as staff handover, when it was not convenient for her to use the toilet.

Yes, I hold it for a long while. They can't come at certain times coz they have got changeover, they have to have a meeting you know – the changeover and you've got to wait, you can't go and that's it and then its too late and accidents happen. You try not to but you can't always hang on. ...(NH3:3:7).

One participant, a hospital patient, who preferred to use the commode explained how not being given a choice had enabled her to regain some control over her continence.

They bring me a commode and I stand up and they put me back onto it. That's what I like best. I wasn't given a choice, they did it and I ask for it now. (H2:3:2)

It is interesting that the participants in our study sometimes felt that necessity took priority over choice and the desire to be clean was more important than being offered choice over the way it was done. Some also felt that institutional routines provided some security and predictability. It is possible that they had learnt to take this view as part of an acceptance strategy but also that choice for them in dealing with incontinence was not essential. However, the participants did note that toileting in bulk to fit around the needs of the nursing home resulted in pain, accidents and loss of dignity. In the next section we explore the views of participants on another aspect of choice in care, the gender of carer.

(ii) Gender of carers: an issue of choice

Earlier in the report we discussed the importance of relationships for older people and the positive impact such relationships can have on dignity and sense of self worth. Staff shortages and the use of agency staff often meant that continuity of care was hard to deliver and patients or residents had little choice over who would give their personal care. Older people are often stereotyped into what others imagine they will like or dislike. When asked about choice in care, our participants displayed a range of views. In general, they were open minded and flexible about how care was delivered as long as it was efficiently and pleasantly carried out, although preferences were expressed.

A nursing home resident who suffered from multiple sclerosis explained that she would not mind who carried out her care as long as it was done efficiently, carefully and did not cause her pain.

I wouldn't no, it wouldn't worry me at all as long as they do their job quickly and efficiently and... I'm looking for a word, ... that they don't be rough with me..... yeah because I hurt. (NH2:2:7)

Participants did express personal preferences but the issue of acceptance emerged again, with participants ready to resign themselves to whoever came along. A male nursing home resident preferred to have a male carer because he felt more comfortable with someone of his own gender:

One would always prefer the male nurse, you know, whenever ... although, they're both equally good but if you give me a choice I'd rather the ... well, you sort of feel happier, if you like. I suppose it's like a girl having a baby, she'd much prefer to have a nurse around her..... But it doesn't bother me, no, you get used to it. (NH1:4:3)

Initially in discussing their preferred gender of carer, some participants had been surprised about male nurses delivering personal care but they spoke of 'going with the times' and getting used to it. A female nursing home resident preferred male carers as she felt they were more caring:

I prefer males to females; they take more care of you, funnily enough. The girls are alright. There is one or two I can't get on with. (NH3:3:4)

Despite these expressed preferences, they realised that in reality choice was limited.

I must say at eighty two going on eighty three I prefer to be with ladies, I know that it is sometimes impossible but that is something I would prefer.(H2:2:6)

However, participants felt embarrassed about exposing their bodies and accepting personal care from younger carers.

Like all main problems, no matter what age I think you are, you get embarrassed when you have to bare your body to sort of the opposite sex like. Otherwise I've got no other sort of objections.... I find it embarrassing, I mean cause they're all young chaps, like you know. I mean I feel like, its like I'm letting me grandchildren, my grandson, look at me.(H1:4:1)

4.3.9 Comment

Choice was a central issue in a campaign led by Age Concern (2003) to improve privacy and dignity in continence care in all care settings. The report states that '*People's choice is paramount. Their views should be sought and respected*'.(p.6). Being involved in decisions about care and making personal choices is seen as an essential part of good practice and dignified care. However, in our study, when we asked about choice and intimate personal care we received a number of replies which call into question the assumption that choice is seen as an important part of good quality care. Firstly, some people appeared to suspend their usual values when accepting care. While this was evident in both settings, it was particularly so in hospital, where getting better became the priority and was more important than having choice. Nursing home residents felt that in relation to continence care, they wanted incontinence dealt with quickly and efficiently and choice was not really an issue for them. It is possible that these participants had gone through an adjustment period and reached a passive acceptance of the situation, but this could also be seen as positive strategy for coping with embarrassment. However, where care was delivered in bulk and fitted around the needs of the institution, participants suffered loss of dignity.

In relation to the gender of carers, although they expressed personal preferences, participants demonstrated flexibility and openness to change, the most important factors for them being the personal qualities of carers, such as gentleness, as discussed in the previous section on professional care. The young age of carers was something which caused embarrassment for our participants as they thought about their own grandchildren giving them care. Most were realistic and acknowledged that choice over the gender of carer was unlikely.

In the next section we discuss privacy in care and explore participants' views on the factors that impacted on privacy in care.

4.3.10 Privacy

Within the two settings, privacy in the nursing homes was easier to achieve than the hospital, as the nursing home residents received care in single rooms and many of them had en-suite facilities.

Yes, you can't get no more privacy than this, door locked, no one can walk in and walk out while you're being seen to (NH1:1:7)

Having his own space and the door locked ensured that this participant felt secure about privacy. Staff always knocked before entering the participants' rooms:

Even if they know you are on your own, they always knock. I say to them "why you knocking for, you know". They say "we have to, we have to knock, to make sure everything is alright ". (NH3:3:6)

Not all residents liked to have their door shut all the time as even though it ensured personal privacy it increased their sense of isolation. One participant, a man who had very little sight explained:

I have privacy here, yes but I have wished for that door to be left open but on the other hand that door could be closed all the time I wanted it but I don't mind it, I want it open all the time (NH2:1:8)

Another resident described how there were different circumstances which determined whether or not she wanted her door open but she definitely did not like to have it closed when she was alone:

What I don't like is having the door shut all the time. You can't have the door open because you are supposed not to, but I do. I have it closed then, I have it about that much closed. I don't mind that. ..I don't mind if somebody is in here, it is nice to have the door closed coz people don't know whose in then. Anyway sometimes you have to have it closed because you are stark naked and what not. (NH3:3:6)

Privacy was potentially more difficult to ensure within a hospital ward as unless patients were in a single room staff were dependent on the use of curtains which were not sound proof and were occasionally ill fitting. The majority of hospital patients in the study felt their privacy was maintained both in terms of use of the curtains:

.....like when you use a commode or anything like that or if the doctors come round, they pull the curtains right down so that it's completely private. The rest.. when you're getting into bed and things like that, they do that, to save you exposing yourself, no they're very very good.(H2:13:4)

And they had the opportunity to use a private room when confidential matters needed to be discussed:

They're really confidential, yes I mean if you've got visitors and there's anything private, you know, that you really wanted to say, as I say, you could go down to that little room or sometimes you can draw the curtain, you know, pull it round. If you need it you can do.
(H2:11:7)

However, one participant who valued confidentiality highly particularly about her incontinence, felt that conversation within the curtains was not always discreet:

.....sometimes they tend to talk louder so it doesn't stay behind the curtains. I think they forget they are curtains. Not their fault, they have a lot to do. I don't like it but then there is nothing I can do about it. I can't say shut up and lower your voice butthat would be rude.
(H2:1:6)

One of the hospital wards was mixed-sex but divided into single sex bays and one participant mentioned her concern that the curtains fitted properly when she was getting changed.

You know like whether if you've taken all your clothes off and these curtains are joined properly so anyone ..'cause there's men and women around, that they're joined and they're really good in this ward
(H2:5:2)

4.3.11 Comment

Privacy and dignity are often linked together in health and social care policy. The Department of Health (2003) produced patient centred benchmarks for good practice, factor 6 relating to 'privacy dignity and modesty'. The Department of Health's report (2007) on mixed sex accommodation in hospital wards focused on a single aspect of care but acknowledged that privacy and dignity pervaded all aspects of personal care. Levenson's (p.17, 2007) report commissioned by Help the Aged identified privacy as an important aspect of dignified care which encompassed having personal space and being able to conduct ones affairs without being overheard or seen, particularly important in hygiene and continence care. The Health Care Commission's Report (2007) added other elements of privacy such as patients not being exposed while receiving care and provision of single sex accommodation.

Generally participants in our study felt that their privacy was maintained and respected in both care settings. It was easier for the staff in nursing homes to ensure complete privacy as nearly all the residents had private rooms. Staff knocked on the door before entering the resident's personal space to minimise intrusion and maximise privacy. However, although privacy was appreciated during episodes of personal care, some participants did not like to have their door closed at other times and felt isolated from the activity within the nursing home. Hospital wards are public spaces and privacy was more difficult to maintain but most patients felt that the curtains were effectively used.

5 Key Points

5.1 *Defining dignity:*

- Participants found difficulty in defining dignity as it was a complex concept and had different meanings for individuals. Responses indicated that dignity is made up of two dimensions: a personal dimension of factors contributing to identity and self respect, and a second dimension related to how we appear to others and how they treat us.
- Participants felt that incontinence was a threat to dignity as it was a stigmatising condition which carried social consequences. Concealing incontinence and being reluctant to admit to it meant participants were unlikely to seek support from professionals and friends.
- Participants felt that loss of dignity was potentially devastating and reduced their self-worth as a competent adult. Dependence on others for personal care involved revealing incontinence and subjecting oneself to embarrassing procedures.

5.2 *Coping strategies*

- Participants developed coping strategies, such as planning ahead and concealment to help them manage their incontinence and therefore to regain some control.
- Participants living in nursing homes appeared to have accepted and resigned themselves to less than ideal conditions.
- In both settings, participants used banter, humour and apology as ways of defusing embarrassment.

5.3 *Professional care*

- While praising the care received, probing revealed variability in care standards in relation to friendliness, rushed manner and handling.
- Participants were reticent in expressing this variability and tended to attenuate negative comments by wrapping them within a framework of explanatory excuses, such as staff shortages.

5.3.1 Communication

- Participants valued communication which took place within a friendly and enabling atmosphere, and their dignity remained intact when they felt respected, listened to and were seen as an individual and an adult. They valued their relationships with staff, being greeted with a smile and by their preferred name or title.
- Participants enjoyed communication and conversation which enabled them to feel involved and a part of things, and they appreciated staff speaking to them in an appropriate manner and with a friendly tone of voice.
- Reassurance and sensitivity was particularly important for participants as they felt embarrassed about their incontinence.
- High staff turnover made it difficult for participants to develop relationships, particularly those who had sensory difficulties.
- Older people often have sensory impairments such as poor sight or deafness which impact upon their ability to communicate effectively. Ineffective communication increased the likelihood of misunderstandings and older people feeling isolated and left out.
- Participants sometimes struggled to understand staff who either had strong regional accents or for whom English was a second language.

5.3.2 Personal Care

- Participants were generally very satisfied with their care and wanted continence care given promptly, efficiently and privately. Willing and friendly delivery of care helped participants to feel reassured and minimised feelings of being a burden.
- Individual participants had developed ways of managing their incontinence and it was important that staff were aware of their individual needs. In addition, participants mentioned how they appreciated confidentiality about their personal details and discreet communication around episodes of care.
- Participants stated that it was important for them to feel clean and that they were cared for in a hygienic environment. A number of participants had painful conditions and stressed how gentle handling helped and added to their sense of feeling like a human being.

- Participants often had to wait to use the toilet despite buzzing and calling for help. At times they were left for long periods on the commode which was uncomfortable and painful.
- Although participants appreciated care given promptly, they did not like to feel rushed and as though they were fitted around a timetable.

5.3.3 Choice and Privacy

- A number of participants felt that personal choice about continence care was not relevant as it was something which benefited them and was necessary.
- While toileting in nursing homes seemed to be carried out in bulk, for example before meals, and which sometimes meant participants were left waiting, some found predictable routines helpful in managing their continence.
- Participants did express preferences about the gender of the carer but the way in which care was delivered was of greater importance. The young age of carers caused concern for a number of participants as it caused embarrassment about exposing their bodies to carers who were the age of grandchildren.
- The majority of participants in both settings felt comfortable that their privacy and dignity was maintained, particularly in nursing homes where single rooms had en-suite bathrooms.
- In the hospital setting, the majority of participants felt that the curtains were adequate in giving them privacy.

6 Conclusions

This interim report draws on the findings from the first phase of the dignity study and has identified the factors which frail older people consider important in relation to maintaining their dignity whilst in care.

It is clear from our interviews and review of existing literature that dignity is a complex concept which has different meanings for individuals. However underpinning this complexity we identified two important themes in older people's discussion, dignity as a sense of self and judgement that individuals make about themselves including their own appearance and dignity as the perceptions, judgement and response of others (see Jacobson 2007). In both senses maintaining dignity when dealing with incontinence is problematic in hospital or residential care. In terms of sense of self, individuals find it more difficult to control key aspects of their personal life, i.e. when and where they use the toilet. In terms of responses of others, older people have to interact with an increased number of people who have the capacity to pass judgement and most of these individuals are strangers who can be critical and who are not influenced by kin or friendship relations.

Incontinence by its very nature is a threat to dignity both internally through loss of control and externally through stigma. When in the community, people with incontinence can take back some control by developing their own coping strategies such as planning ahead and limiting fluid intake but such options are more limited in care settings. Older people make up the majority of incontinence sufferers. They are known to experience ageism when in contact with services; they are often thought to be deferential and worry about being a burden both to their families and to nurses/carers. They also develop coping strategies for managing such as endurance and acceptance. These are not always negative strategies but ways of coping with the situation and getting on with staff.

Institutions such as hospitals and nursing homes are powerful and take control by imposing routines and regimes for care. Despite numerous reports and policy initiatives, individuals and their complex needs tend to get lost within such organisations. Without doubt, person-centeredness is intrinsic to dignified care, but it can get easily compromised in times of organisational instability. Staff shortages can for example contribute towards a less than person-centred service, and this was recognised by our participants by their readiness to make allowances. This in turn could be connected to the 'passive acceptance' of care that we found, that was less individualised and more an outcome of being institutionalised and subjected to organisational requirements.

Difficulties articulating negativity about care can also be linked here. Whether participants sought to protect staff from external scrutiny via the research, or were concerned that their own care would not be affected, was difficult to ascertain. However, there is a generational tendency for older people to place pride and humility in a National Health Service that is free at the point of delivery, when many lived during a time when services were chargeable and

difficult to afford. Passive acceptance of conditions could be a feature of this attitude, coupled with the additional internalisation of being a burden through loss of independence. Further connections can be made to the concept of choice. Again, this is central to policy and practice in relation to individualised care but is another ill-defined word and, as we have demonstrated, may have little actual relevance to people with difficult care needs. Person centred care and planning should therefore endeavour to understand such needs and tensions, but as care plans become more standardised or develop into care pathways, they may become part of tick box exercises which fail to reveal details of how individuals cope and manage.

Further to this, our study demonstrated the continuing importance of effective communication with older people in care settings. To maintain their dignity, older people need to be involved in decision making about their care, be seen as individuals and supported empathetically. Episodes of insensitivity were revealed by the narratives which has the potential to be damaging to feelings of self-worth. To improve this situation, older people need encouragement to articulate what they really feel, the ways in which they usually manage their personal care and be supported to continue their own management whilst they are in care and are able to do so.

6.1 *Strengths and weaknesses of phase 1*

In methodological terms, the qualitative approach used has enabled the elicitation of personal and detailed insight into a subject that has hitherto been ill-defined, and in the context of a condition that in itself is undignified. We have therefore been able to provide a significant contribution to the understanding of dignity in this area, and from the perspective of a target group that is generally under-researched.

Despite difficulties with recruitment, it was clear that some of the most frail people were included. Our study was restrictive however in that we were only able to speak to older people who were cognitively able to give their views. While the study could be criticised for the small numbers from each setting, it is not the function of qualitative research to gain representativeness through large numbers but to ensure that rich data is obtained that provides the study with credible and relevant detail, necessary for the next stage, and this has been assured.

There were some environmental difficulties experienced during data collection that may have had some impact on the ability of the participant to express honest views. In general, we found that our sample tended to accentuate the positive when in receipt of care, and make allowances for any care that was less than optimal. While efforts were made to conduct interviews in private areas to maximise the potential for candid responses, this was not always possible. However despite this, this phase of the study has enabled rich data to emerge in preparation for the next phase.

7 References

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Staff Information Sheet

A study of privacy and dignity in continence care: developing patient based standards and recommendations for care.

Our names are Tara Chapman Helen Alaszewski and we are researchers at the University of Kent. We will shortly be conducting a research study in your nursing home/ward. The aim of the study is to identify how older people with continence problems can best maintain their dignity. This study has three parts to it. Firstly we asked groups of people with continence issues to help us identify what preserving dignity meant to them. We then used this information and current literature to develop and pilot an observation schedule. We are now ready to do an observation phase of the project and your nursing home/ward has been selected.

What is the purpose of the study?

This study is all about finding out the best way for older people who have difficulties with their bladders or bowels to keep their dignity in their nursing homes/a hospital ward. One of the best ways of finding this out is to observe people while they are having their bladder or bowel care. We are particularly interested in finding out about how people's dignity is maintained in nursing homes and on hospital wards. This research will help us to develop some standards of care to help people maintain their dignity during bladder and bowel care in the future.

The study will last for 2 years and it is anticipated that observations at your nursing home/ ward will take place over 12 days in a seven week period [*pilot observation study*]. The results may be published in journals and talked about in research seminars and conferences. The study has been approved by ethics committees and is jointly run by the University of Kent and the Royal College of Physicians, who are funding the research.

What will I have to do?

We would be grateful if you could help us to identify at least 5 [*pilot observation study*] residents/patients with continence problems for this study, and see if they might be interested in taking part. We will give you an

information sheet for the residents/patients, which you may need to read through with them. If they are interested, we would like you to pass on their details to us and we will explain the study in full and get their consent. We will visit you to discuss this further and talk through any queries you may have about this study. We will then return a week later and speak to any residents/patients who have agreed to take part. During our time at the study if there any new residents/patients with continence problems in the ward/home we would be very grateful if you could continue to ask them if they would like to participate.

Residents/patients agreeing to take part will also have to fill out a questionnaire and we may need you to help them fill this in. A Barthel index score and an Abbreviated Mental Test Score will also be taken for each patient and we may also need your help with getting this information.

Which patients will be chosen?

The following is a list of inclusion criteria for patients to take part in the study :

- 65 years or older
- Cognitively or linguistically able to give consent to take part in the observation study.
- Any of: urinary and/or faecal incontinence; requiring assistance with toileting; assistance with the use of maintenance products or assistance with catheter or bowel care.
- Will be in your nursing home/ ward for at least four days before commencement of the study

What will happen during the course of the observation study?

It is expected that the observation phase will take place over 12 days in a seven week period [*pilot observation study*]. This may be subject to change, depending upon the need for further observations and we will keep you informed at all times. However, we anticipate that we will visit your nursing home/ward and will observe for four hours each day over six consecutive days. We will do this on two different occasions. On the very first day of both observation periods, we will observe for two four hourly spans and this is to allow patients to become accustomed to one of us being present on the ward/in the nursing home. Only one of us will be present during the observations at any one time.

The time periods will cover all hours of the day and night and we will let you know in advance when one of us will be coming. We will be looking at privacy and dignity issues centred on bladder and bowel events such as toileting and catheter care and recording my observations on a schedule. We will be observing different patients at different times and will not be observing patients who do not give consent. We would be grateful if you could completely ignore our presence when one of us is in your nursing home/on your ward!

This is a sensitive research study and it will mean that we will be observing patients during toileting episodes, however, we will withdraw at the same time as the nurse. It may be possible that residents/patients become very distressed during observation. We will be very sensitive to this and if this should happen we will ask for your help in reassuring them and making sure that they still want to continue with the observations. If residents/patients continue to be distressed then we will withdraw completely from observation of that resident/patient.

We would like to reassure you that we will not intrude on any aspect of the care you are giving residents/patients and we will not obstruct or interrupt you in your work, unless an emergency occurs where we may need to intervene to call for assistance (such as a cardiac or respiratory arrest, or a person about to fall). We are there purely to observe and identify criteria for best practice.

Alongside the observation we will be collecting other pieces of information. This will consist of a map of the area we will be observing, some details about the number and grades of staff on duty, the number of people in the nursing home/on the ward and numbers of visitors.

How confidential is this information?

All information collected about the study site or staff and patients within the site during the course of this research will be kept strictly confidential. It will be stored in a password protected computer and accessed by one researcher. Once the study has finished, we will destroy any data collected. The site, patients or staff will not be identifiable in any reports that we publish from this research.

Contact for further information

If you have any questions please contact Tara Chapman or Helen Alaszewski at:

Centre for Health Services Studies
University of Kent
George Allen Wing
Canterbury
Kent
CT2 2NF

Tel: 01227 8243 E-mail: tjc23@kent.ac.uk or h.p.alaszewski@kent.ac.uk

Thank you for your assistance!

Appendix 2



Patient Information Sheet

A study of privacy and dignity in continence care: developing patient based standards and recommendations for care.

Our names are Tara Chapman and Helen Alaszewski and we are researchers at the University of Kent. We would like to invite you to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others such as friends, family and staff if you wish. We will be happy to give you some more information about the study, and our contact details are at the end of this information sheet.

What is the purpose of the study?

This study aims to find out the best way for older people who have difficulties with their bladders or bowels to keep their dignity in a nursing home or in a hospital ward. One way of finding this out is to observe events of bladder and bowel care. We are particularly interested in finding out about how people's dignity is maintained in nursing homes and on hospital wards. Incontinence is a common problem which affects people from all walks of life. Lots of people suffer from incontinence although it is not often talked about. This research will help us to develop some standards of care to help people maintain their dignity during bladder and bowel care in the future.

Your participation in the study will be for approximately 12 days over a seven week period [*piloting observation study*]. The results may be published in journals and talked about in research seminars and conferences. The study will run for 2 years has been approved by ethics committees and is jointly run by the University of Kent and the Royal College of Physicians, who are funding the research.

Why have I been chosen?

You are being invited to take part because you have some bladder or bowel difficulties. Also because you expressed an interest to staff that you may take part. We will also be inviting other patients with similar problems to take part in this study, and there should be approximately 5 [*pilot observation study*] people in your home/ward in total.

Do I have to take part?

It is entirely up to you whether or not to take part, but if you do not want to take part, this will not affect your care in any way. If you decide to take part but change your mind, you are free to do so and withdraw from the research, and this will also not affect your care.

What will happen to me if I take part?

If you do decide to take part you will be asked to sign a consent form. You will then be asked to fill in a questionnaire that records information about your bladder and bowel difficulties and some questions about your quality of life. One of us or the nurses can help you fill out this questionnaire if you want. There will be another two very short assessments of your physical and mental health. All of these will help us to find out whether you are able to take part in this study and this should take no more than a few minutes of your time.

During the study, one of us will be present in the nursing home/ward and will be in the background looking to see what happens when you have any bladder or bowel care, and recording this on a schedule. The type of things on the schedule could be things such as looking at the general environment you are in, interactions you have with other people, how many people are on the ward, etc. We would be grateful if you could completely ignore our presence when one of us is around! We will not intrude in your care in any way and are only there to observe just like a 'fly on the wall'. All patients who consent to taking part in this study will be observed during this time. Only one of us will be present during the observations at any one time.

We may ask you to have a look at the schedule sometimes to see if you agree with what we are recording about your bladder and bowel care and how dignity is maintained.

We would like to point out that taking part in this research will mean that one of us will be observing you during toileting episodes, but we will not actually observe you whilst you are on the toilet. If at any point during the observation you suddenly decide that you don't like being watched any more and it is upsetting you then please let us know. If you decide that you really don't want to take part in the study any more then we will stop observing you.

We will be observing a number of patients over approximately 12 days in a seven week period [*pilot observation study*]. We will observe for four hours each day over six consecutive days covering all times during the day and night. We will do this twice. We may be there for a shorter or longer period but we will let you know in advance when one of us will be coming. We will be recording observations for four hours at a time. On the very first day of observation we will observe for two four hourly spans and this is to allow you and other patients to become accustomed to one of us being on the ward/in the nursing home.

Will my taking part in this study be kept confidential?

We would like to reassure you that any information collected about you will be strictly confidential. It will be stored in a password protected computer and accessed by one researcher. Once the study has finished, we will destroy any data collected about you and you will not be identifiable in any written report.

Who do I contact for further information?

If you have any questions please contact Tara Chapman or Helen Alaszewski at:

Centre for Health Services Studies
University of Kent
George Allen Wing
Canterbury
Kent

CT2 2NF

Tel: 01227 8243 E-mail: tjc23@kent.ac.uk or h.p.alaszewski@kent.ac.uk

Thank you for your assistance!

Appendix 3

Individual interview schedule

Introduction

Hello. Thank you for coming. Name. Where from.

Today we are going to talk about dignity. I would like to know your experiences and feelings about this subject, especially what can be done to help you maintain your dignity with regard to your continence needs in the nursing home/hospital ward.

This discussion is in strict confidence and nothing that you say today will identify you with our research. I really want to look at improving situations and therefore I am interested in your personal concerns and the experiences you have had. There are no right or wrong answers and if you have any worries or concerns then just stop and ask me. The discussion will be recorded, but again everything is in strict confidence.

Introduction:

Before we start to discuss dignity and privacy, could I just ask a few short questions?

Would you mind telling me how old you are?

Approximately how long have you lived in this home?/how long have you been in hospital/what brought you in?

1. Nursing home experience/Hospital experience

- (i) Thinking about your experiences here, can you tell me what kinds of things are important to you in making you feel respected**

Prompts

- Independence, being listened to, privacy, treated as an individual, given choices, equal rights.

- (ii) Could you tell me a bit about your continence problems**

Prompts

- What sorts of things do you need help with?
using the toilet, changing clothes, washing self

- (iii) Are there any times particular times that you feel you do feel respected? Can you think of any examples of this?**

- (iv) Are there any particular times when you do not feel respected? Can you think of any examples of this?**

Prompts

- Dependency – fragility
- Body not functioning like it used to – bodily functions

- Gender– do you think it is important whether it is male or female helpers who care for you
- Pain
- Situations where you felt, embarrassed, degradation, ridiculed, shamed, humiliated foolish – being incontinent, loss of control
- Exposure – being made to wait for care
- Proper assessment
- Choice of what home you wanted to be in – finance

(v) What do you feel can be done to help make you feel more at ease with regards to your continence needs?

Prompts

- Toilet prompting and schedules
- Bed protection
- Choice of pads
- Help received – nature of help received.
- Advice on skin care

2. Professionals

(i) I'd like to look particularly at how you feel you are treated by the staff and the care you receive in relation to keeping your dignity. We are going to look at specific things and I want you to give me examples of your experiences.

(ii) Communication: How do you feel about the way you are spoken to in the home/hospital?

Prompts

- Language
- Tone of voice
- Respect

(iii) Care: How do you feel about the way care is given?

Prompts

- Choice – therapy, pads, catheter, when to go to the toilet, bathing, dressing
- Control – (clothes given to wear, communal clothes)
- Consultation of views

(iv) Attitude: How do you feel about the attitude of the staff treating you?

Prompts

- Boundaries – being discrete
- Professional attitudes and behaviour

(v) Describe to me an example of when you felt you had been treated with dignity during a time when you were getting some care for your continence.

- (vi) **Were there any times when you felt you lost your dignity when you were getting some care for your continence.**

3. Environment

- (i) **Thinking about your surroundings, is there anything that affects your dignity?**

(probe deeply)

Prompts

- Privacy – Do you have much privacy
- Access to facilities – Is it easy to go to the toilet, can you make your own drinks

- (ii) **General environment: What sort of things affect your dignity:**

Prompts

- Noise, lighting, activity, neighbours, number of people in the home, strangers, safety, family visiting

4 .Feelings about dignity

- (i) **Now we are going to ask a very general question about dignity
What does dignity mean to you?**

- (ii) **Are there any aspects of personal care that you feel are important for maintaining your dignity?**

- (iii) **What things make you feel that you are being treated with dignity?**

Prompts

- Respect, independence, self esteem, equal rights (ageism), consideration of emotions, privacy, being seen as an individual, being listen to, taken seriously

- (iv) **Dignity and others – do you think dignity is linked with how people behave towards you?**

Prompts

- Family, staff

- (v) **What factors take dignity away from you?**

Prompts

Staff issues, family issues, levels of understanding, communication issues, insecurity, income, poor health, not being able to take part in decisions, dependence.

