Dignity in older age: what do older people in the United Kingdom think?

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Abstract

Background: Dignity is a complex concept and there is little empirical research to show how older people view dignity. This study, using qualitative methods, explored the concept of dignity from the older person’s perspective.

Methods: 15 focus groups and two individual interviews were conducted in 12 different settings, with a total of 72 participants. Participants were purposively sampled to ensure a mix of socio-economic status, ethnicity, gender, age (65+) and level of fitness. Focus groups were audio-taped and transcribed. The method of constant comparison was used to analyse the data.

Results: There was strong evidence to suggest that dignity was salient to the concerns of older people. Dignity was seen as a multi-faceted concept: (i) dignity of identity (self-respect/esteem, integrity, trust); (ii) human rights (equality, choice); and (iii) autonomy (independence, control). Examples of dignity being jeopardised rather than being enhanced were given. A loss of self-esteem arose from being patronised, excluded from decision-making, and being treated as an ‘object’. Lack of integrity.

References


Received 25 February 2003; accepted in revised form 18 September 2003
in society meant that there was an inability to trust others and an increased vulnerability. Equality was an important issue but many felt that government policies did not support their rights.

**Conclusions:** this work identifies the different ways dignity is conceptualised by older people. The evidence showed that person centred care for older people needs to be specifically related to communication, privacy, personal identity and feelings of vulnerability. It provides evidence for policy makers and professionals to tailor policies and practices to the needs of the older person.

**Keywords:** dignity, older age, qualitative research

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### Background

National and international policies for the health and social care of older people increasingly emphasise the right to and the need for dignity [1–3]. Despite these documents, there is evidence of undignified treatment in health and social situations, especially in relation to older age groups [4–7]. Furthermore, the term dignity is rarely defined and little empirical research has been undertaken in relation to older people’s experience of dignity.

There is evidence to suggest that treating someone with dignity may impact positively upon treatment and social outcomes [8]. Also, research has indicated that feeling valued and appreciated is important to mental well-being [9]. Undignified treatment may also have a detrimental economic effect due to the increase in formal complaints [10]. This qualitative study explored the meanings and experiences of dignity from the perspectives of older people. The study forms part of an international project comparing older people’s views from different European countries [11].

### Methods

Focus group discussions were used as the main method of data collection. The groups were held in cities in South West England and South Wales, between April and October 2002. Participants were chosen to represent a mix of socio-economic status, ethnicity, gender, age (65+) and level of fitness. However, within the focus groups we attempted to promote homogeneity of group members to avoid potential hierarchical problems. Despite the recommended number of participants per group being between 8 and 10 [12], after conducting a number of focus groups with varying numbers of participants, it was evident that the optimum number was four to six. Groups with more than six participants lacked cohesion, and those with less than four participants tended to lapse into serial questioning. Fifteen focus groups and two individual interviews were held in a variety of settings, involving 72 out of 108 invited participants (see Table 1). A semi-structured schedule was developed to explore the participants’ perceptions of dignity. The facilitators were well trained in conducting focus groups and attempted to include everyone in the discussion.

Data collection and analysis continued concurrently according to the constant comparison methods of grounded theory [13]. Focus groups were tape recorded and fully transcribed. Data were analysed by detailed scrutiny of the transcripts to identify themes, which were then coded using Atlas.ti. These themes were then compared with each other in separate word processing files. Data were examined for similarities and differences within themes and descriptive accounts were written, retaining the context of the discussion. Two researchers independently coded the transcribed data. These codes were compared and agreement was reached by discussion. Simultaneous sampling and analysis continued until all categories were saturated and no new information was forthcoming. Negative cases (examples against emerging themes) were investigated closely. The themes that emerged from the data are presented together with illustrative quotations. All names have been changed to numbers to preserve anonymity.

### Findings

There was strong evidence to suggest that dignity was salient to the concerns of older people. However, it was a problematic concept in that it was easier for people to talk about its absence, or about being treated in an undignified manner. Furthermore, terminology has changed over the years, with alternative terms such as ‘respect’, ‘equality’ or ‘pride’ being offered instead of ‘dignity’. Three major categories emerged from the analysis, including (i) dignity of identity, (ii) human rights and (iii) autonomy. It must be emphasised that these are inter-related and each category contains several sub-themes.
The context in which dignity was talked about freely was mainly in relation to health and social care settings. However, informants did identify other aspects of dignity. For example, the younger, fit older people emphasised broader issues associated with rights and policies for older people.

**Dignity of identity**

This category contained the majority of the themes and included dignity ‘as it affected the self’, dignity in relation to other age groups, and dignity in relation to health care personnel. The importance to an individual’s self-identity and self-respect was cited:

> I think this is up to the person themselves, if they have lost their dignity within themselves and they no longer think that they are a person that matters. [U3A]

Informants discussed other people losing their self-respect, for example, those who had ‘let themselves go’ or ‘given up’ on their self-care or appearance. Being excluded from conversations was also a sign of disrespect and participants felt that people were belittled because they were old. Dignity in relation to younger age groups was discussed and many believed that their experiences should be appreciated by younger people:

> I think age, it teaches you a lot, you know a lot more. But younger people shouldn’t disparage elderly people because young people have to learn what the old people have already learnt. [Older People’s Forum]

Looking ‘respectable’ was important to participants to maintain their dignity, regardless of age, illness or income. Participants stated that lack of attention to people’s appearance by hospital or residential staff, such as haphazard buttoning of clothes or dishevelled dress, reduced dignity. Furthermore, dressing residents in fancy dress in care homes was thought to be degrading:

> Another thing when they dress them up in stupid fancy dress, some like fairy dolls, oh how degrading. [Health Shop]

The visible signs of ageing were thought to lead to disrespect from others. For example, grey hair made people feel anonymous, or treated as a child. Participants mentioned disrespectful labels attached to old age such as ‘cotton buds’, ‘wrinklies’, ‘bed blockers’ and ‘geriatrics’.

Dignity was related to the interactions with health care personnel. Dignity was often violated in hospital by staff exposing their naked bodies to strangers when, for instance, a hoist was used for lifting:

> On the hoist and I used to say ‘can I cover myself up’ and they just pulled your nightie down over you but the back view was wide open to anybody. [Stroke Rehabilitation Unit]

In some cases, exposure was reduced by the staff covering people with towels. Some participants, especially those from nursing homes, stated that they had become accustomed and accepted this situations; however, others suppressed their feelings. Drawing curtains around beds was seen as a way of maintaining a person’s dignity but this was done inconsistently. Mixed wards and being nursed by men were deemed undignified by female participants:

> I don’t think that’s dignity at all. Why should men and women, not your husband, but why should they be sleeping next door to you. He is not your husband. When you come out of the bed and maybe your clothes pull up and the man can see everything, there is no privacy there. [Community Centre]

Dignity was jeopardised by suffering. Dying without suffering (‘to go in your sleep’, or ‘as peaceful as possible’) was seen as a dignified death. The role of health professionals was discussed in relation to death with dignity. Washing, powdering and maintaining verbal contact with the dying person were given as examples of dignified care. On the other hand, undignified deaths included dying alone or staff not changing the person into clean clothing:

> They [hospital staff] knew he was going to die that night, and a nurse came and it was a real hard sort of nurse and my friend said ‘can we wash him and put him into his clean pyjamas’, and she said ‘oh don’t put him in clean pyjamas, he is not going to be here much longer’. And she said to the nurse ‘it’s his dignity, I want him washed and changed’ [Health Shop]

Forms of address either enhanced or jeopardised dignity. The main discussion centred on being addressed in a casual manner or by their Christian name by hospital staff. Participants felt patronised by being called ‘love’ or ‘dear’ and the use of Christian names was seen as disrespectful and intrusive. This was thought to be more offensive for older people due to their upbringing:

> I think that is a pity if you call an older person by their first name [Pt 12: its your testing of a relationship. To call someone by their Christian name when you first meet them... it won’t happen to our generation...]. [Sheltered Home]

Possible reasons why older people did not complain about first-naming included not wanting to appear old-fashioned and feelings of vulnerability:

> Since a sizeable portion of the population would be offended by being addressed by their first name, the more formal approach would be advisable. I don’t see it happening. Why don’t patients complain? First of all they don’t want to be thought stuffy. Also patients, recognising their vulnerability, will bend over backwards not to offend the people in whose hands they find themselves. When asked to give thought to issues of dignity and psychosocial matters you may think title is a minor expression of dignity, but it is perhaps one of the few left to people struggling to maintain that dignity in the face of paralysis or incontinence. [Health Council]

Other themes raised were integrity and trust, although this was thought to be absent in today’s society:

> You can’t trust nobody these days Pt 62: its about trust and that’s related to dignity, they know who live round here alone because they watch and they don’t see nobody with you. [Community Centre]

**Human rights**

This category included the themes of human dignity, human rights and equality. Being human involves possessing an intrinsic dignity that is inalienable. Statements such as ‘every human being has dignity’, and ‘everyone should be treated as an individual’ were used to describe human dignity. Being treated
as an equal, regardless of age, was also important. Certain circumstances led to inequalities, for example, the sense of inferiority older people feel while in hospital:

"It's about elderly people in hospital. Patients don't possess the health, vigour or knowledge of those looking after them, which means that they're in an unequal situation. In fact, they're in a position of decided inferiority with regard to health, vigour and knowledge." [Health Council]

The participants believed younger people are more willing to question and exercise their right to be heard whereas older people are reluctant to assert their views. This may represent an inherent passivity in older people when in health settings.

Participants highlighted the importance of the right to choose how they lived. Furthermore, euthanasia was highlighted as an example of the right to end a life deprived of dignity:

"Having my dignity maintained by still being able to make those choices about how I should die. I had no choice about being brought into the world but I hope and want a choice about how I should depart from it." [Health Council]

It was thought that due to advanced medical interventions, death had become medicalised:

"I think we are a death denying society but I personally feel that death is natural, it's time to die just go, why keep prolonging it, when doctors are taking power, they control too much, even death is medicalised." [Health Shop]

The majority of informants were in favour of self-determined death. Living wills were viewed positively as they promoted individual choice on treatment alternatives:

"I think this living will thing is a very good thing. As long as you have done it when you are in your right mind and it is written on your card that you don't want any resuscitation." [U3A]

Government finances and policies were deemed inadequate to support the rights of older people. For example, an older woman was denied provision of two care assistants due to lack of finances. The issue of pensions further emphasised this point as participants argued that UK pensions were insufficient:

"We maintain that normal pensions unassisted is far too low. When we wrote to the MP's about this, the replies I got were most unsatisfactory and one used the demographic factor as the reason. The reason that British pensions are too low is because we have a larger proportion of older people in relation to young earning people contributing to the common wheel." [Older People’s Forum]

Autonomy

The third major theme to emerge in the discussions of dignity was capacity for independence and autonomy. Participants wanted to remain independent, have control over their lives for as long as possible, and maintain their mental/thinking ability. However, it was often either their children, financial difficulties or the loss of their partner that reduced their independence. Some participants, particularly those in nursing homes believed that some people, because of their upbringing, were too stubborn to give up their independence and, therefore, become undignified. Those who were not in residential or nursing homes stated that being told to perform activities at certain times threatened their autonomy:

"I think that's the thing about going into a home isn't it, you're not independent, you can't do what you want... Pt 13: Set times for meals." [U3A]

Participants in nursing homes stated that they had accepted the lack of autonomy associated with their changed situation and their priority was to be kept clean and tidy to retain their dignity. This may represent an adaptation or acceptance of their changed life situation.

The fear of being a burden on society and family was a key issue related to dignity:

"Well they [social workers] bounded me... you just feel you are a burden. I felt a complete burden, that I should stay in hospital forever or just fade away... that my useful days are over, it was condescending." [U3A]

Related to autonomy was an individual's freedom of choice. The following quotation about social services shows that personal choice was denied when a person is old or they have a disability:

"They want you to do exactly what they want you to do and that’s what I have really objected to... they are taking my choice away, they seem to want to take your choice away, they don’t want you to have an opinion, they want to tell you 'you will wear pads', ‘you will go to a day care centre’." [Health Shop]

Discussion

The aim of this paper was to explore the beliefs and meanings older people associate with dignity, by examining the perceptions of older people from a range of different socio-economic backgrounds, levels of health and disability, who live in institutional and community settings. Previous studies have tended to focus on older people with specific problems or in residential or hospital settings [14]. This work forms part of a European study examining cultural similarities/differences of dignity in older age. As a consequence, focus groups were used as the main method of data collection in order to gain an insight into group norms and cultural/social perspectives. However, caution should be taken about the sample as they are self-selected and under-representative of ethnic minorities.

The evidence suggests that policy documents and professional codes are correct in emphasising the importance of dignity for older people as the evidence clearly showed that dignity was salient. Although participants cited instances where their dignity was maintained, the evidence indicates that people are being treated in undignified ways. Dignity was shown to be multi-faceted and described as
three different dimensions: dignity as identity, human rights and dignity as autonomy.

The concept that appeared to be most prevalent to dignity was ‘identity’. This evidence confirmed results from previous studies that dignity is challenged through negative interactions between staff and patients [15, 16]. The informants also reported evidence of humiliation, poor communication and exclusion and a general insensitivity to their needs. Dignity as autonomy was highlighted as important and participants were concerned about maintaining autonomy and remaining independent, without being lonely or lacking support. Older people were particularly concerned about being a burden on their families and the state. This appears crucial as there is evidence not only that older people easily become disempowered in health and social care settings but also, that being included and having control in health care decisions can result in positive health and social outcomes. Certainly autonomy and control appear to be threatened when patients are not given adequate information or the opportunity to understand fully their diagnosis and make informed choices about their care [17, 18].

There were also more general concerns expressed about dignity as a right, which included being treated as equals and having the right to choose how they should live and be cared for. This identification of dignity as a fundamental human right might reflect its increasing jeopardy in health and social care where it cannot now be taken for granted. Alternatively, emphasis on rights may reflect the so-called growth of the enlightened consumer and the attempts to change the negative images of old age as hardship and degeneration to a more positive one of old age as fitness, activity and fulfilment [19]. Evidence for both these images were found in this study depending on the focus group setting, and certainly in groups involving the young-fit-old there was awareness of the rights of older people. The old-frail informants tended not to articulate dignity in terms of rights and were more concerned about their identity being jeopardised by undignified practices.

At a time when notions of choice, empowerment and consumerism are high on policy agendas there is clearly room for considerable improvement in current practice. The introduction of the National Service Framework for Older People [1] pinpoints at least some of the concerns about dignity articulated by older people such as the need to root out age-discrimination for eligibility to services and the need to maintain a balance between care and support and independence. It also emphasises the need for person-centred care, which was central to the concerns of older people in this study. However, this study indicates that person-centred care for older people needs to be specifically related to communication, privacy, personal identity [20], and feelings of vulnerability. According to participants, these important aspects of dignified care are not currently being addressed by professionals, who appear to have little time for such ‘quality’ issues. It is important, however, that frontline staff are not scape-goated and although training may improve quality of care, the focus should be on the whole system of care and how best to prevent degrading treatment [21].

Key points

- A qualitative study of 72 older people showed that dignity was salient to the provision of health and welfare services.
- Dignity was conceptualised as ‘dignity as identity’ (self-respect, self-esteem, pride, integrity, trust), ‘human rights’ (equality and human entitlement to dignity) and ‘dignity as autonomy’ (independence, self determination, freedom of choice).
- Dignity was challenged through negative interactions between staff and patients, a lack of privacy, poor communication and a general insensitivity to their needs.
- Older people are concerned about maintaining their autonomy but felt a burden to society and their families.
- Older people wanted to be treated as an equal but felt that government finances/policies did not support their rights.

Acknowledgements

We thank all the study participants for giving their time and information. We also acknowledge Stephanie Sivell for facilitating the focus groups and helping with the analysis.

Conflicts of interest

There are no conflicts of interest in this study. South West Local Research Ethics Committee has reviewed the ethical standard of this study.

Funding

This project is funded by the European Commission Fifth Framework (Quality of Life) Programme – Contract No QLG6-2001-00888. The Department of Social Medicine at the University of Bristol is the lead centre for the Medical Research Council’s Health Services Research Collaboration.

References

Patterns and determinants of alcohol consumption in people aged 75 years and older: results from the MRC trial of assessment and management of older people in the community

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Abstract

Background: very little work on alcohol consumption patterns in older people has been undertaken. As a result, knowledge about the prevalence and characteristics of regular drinkers and heavy drinkers in this age group remains limited.

Objective: to determine the socio-economic and health characteristics associated with different levels of alcohol intake in older people.

Design: detailed screening of patients in one arm of a cluster randomised trial.

Setting: 53 UK general practices drawn from the Medical Research Council General Practice Research Framework.

Subjects: all patients aged 75 and over on the GP lists (excluding those in nursing homes or other long stay care) were invited to participate in the study. Of the 15,358 people who received a detailed assessment in the ‘universal’ arm, 14,962 (97%) of these answered questions on alcohol consumption. Of these, 62% were female and the median age was 80.3 years.

Methods: associations between reported alcohol intake and various socio-economic and health variables were investigated, first in univariate analyses and then controlling for other variables in logistic regression models.

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