

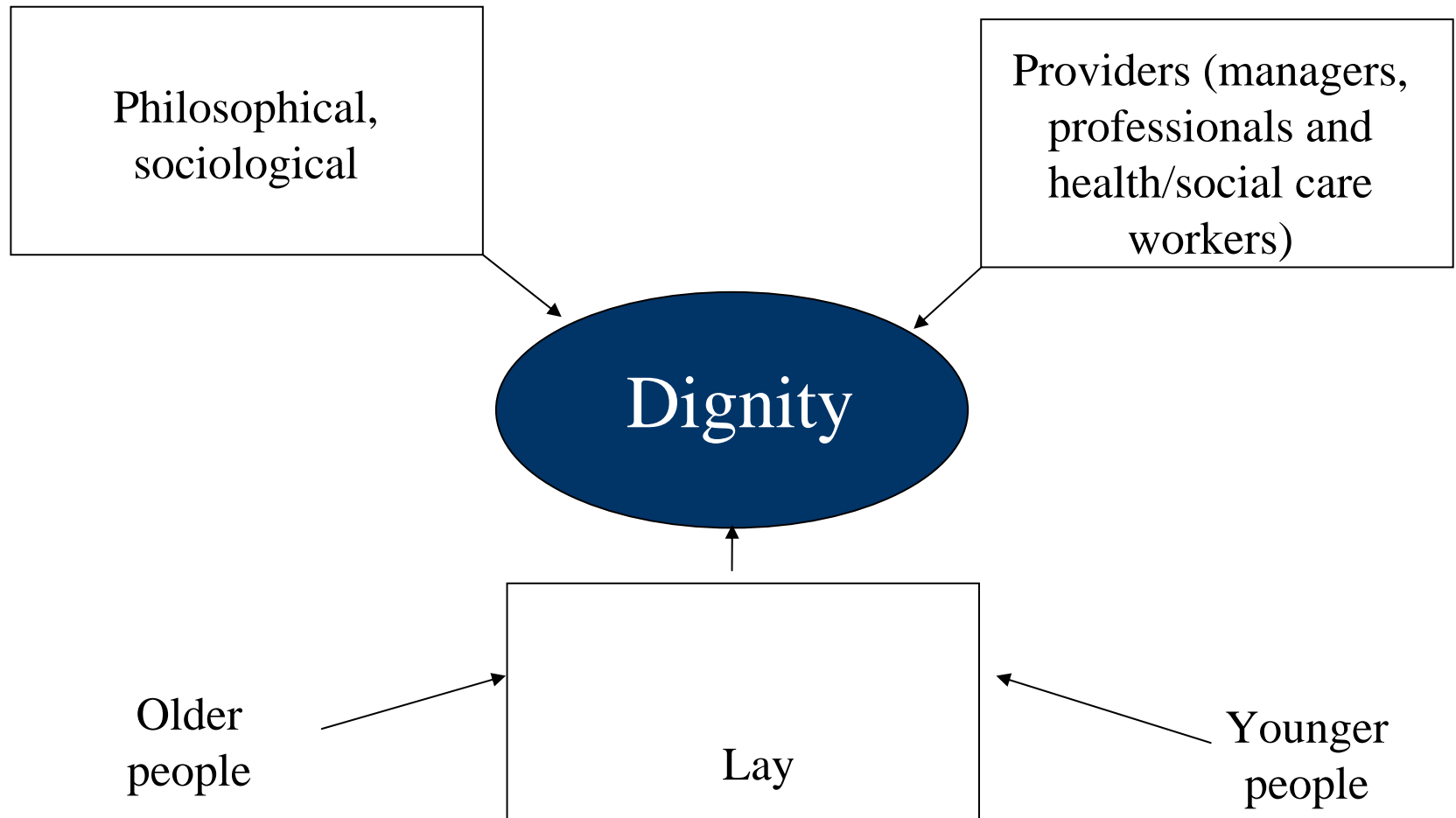
DIGNITY UNDER THREAT : **Provision of care for older** **people**

Michael Calnan and Win Tadd

Why examine dignity?

- Emphasis
 - In policy on the right to and need for dignity in older age
 - Professional codes of ethics/conduct
 - Negative stereotyping/discriminating practices detract from social worth and self-esteem of older people
- Dignified practices influence treatment/social outcomes and mental well-being
- Evidence of violation of human dignity
- Little evidence
 - Of how older people and health care workers view dignity
 - Of how dignity can be promoted in health and social care
 - Dignity rarely defined

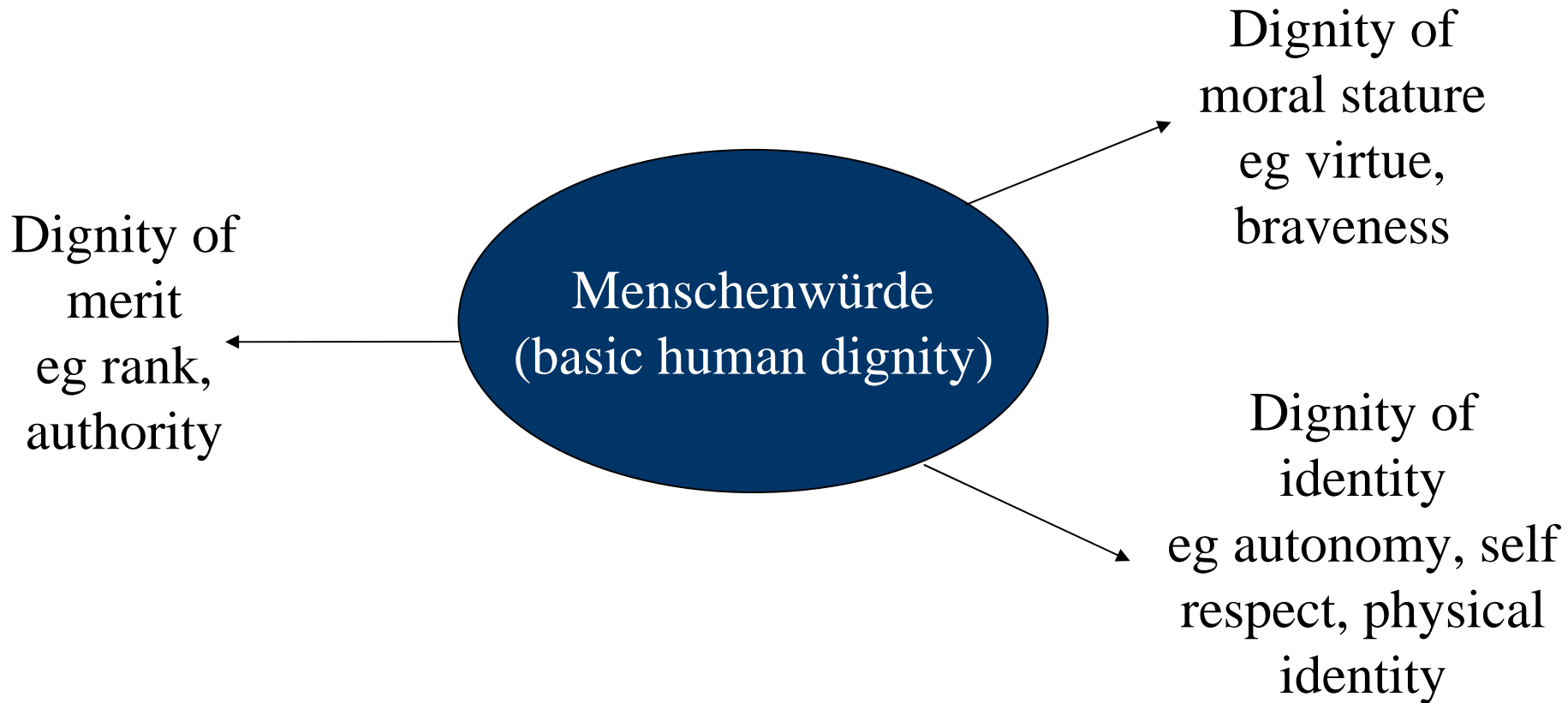
Perspectives on Dignity



Philosophical concepts of dignity

- ‘A dignity always has a ground. In the case of Menschenwürde the humanity is the ground. In the case of the dignities of merit, the merit constitutes the ground. In the case of the dignity of the moral stature, the morality of the person is the ground. And in the case of the dignity of identity, the integrity of the person as a whole is the ground.’ Nordenfelt (2002)

Philosophical concepts of dignity



Theories of recognition

R Sennett

- Social inequalities encourage lack of respect and recognition for others in modern society as respect and recognition given only to those equal in strength and resources.

A Honneth

- Mutual recognition central to human relationships
- Without mutual recognition there could be no sense of dignity/indignity
- Key elements of theory of mutual recognition
 - Relationship to oneself intersubjective process
 - Depends on other attitudes to oneself
 - Establishment of relations of mutual respect for self realisation (self respect)

Dignity under threat: Ageing and older people

- Contexts in which dignity enhanced or threatened
- Life course – stages where dignity at high and low point
- Vulnerable – lack of resources to protect autonomy and resist dependency and exclusion
- Old age hardship
 - Poor health
 - Low levels of income
- Dignity threatened
 - Collectively as citizens
 - Individually in daily life

Objectives

- To examine how older people, health and social care providers and younger and middle aged people in the UK viewed and experienced dignity in later life
- To consider how different contexts in UK society affect older people's experience of dignity

Why focus groups?

- To help to identify cultural values and facilitate cross-cultural comparison
- To highlight the informants attitudes, priorities, language and framework of understanding

‘Group discussion is particularly appropriate when the interviewer has a series of open-ended questions and wishes to encourage research participants to explore the issues of importance to them, in their own vocabulary, generating their own questions and pursuing their own priorities.’

Kitzinger J. In: Pope C and Mays N (eds), Qualitative Research in Health Care, 2000,20-29, BMJ books.

Sampling

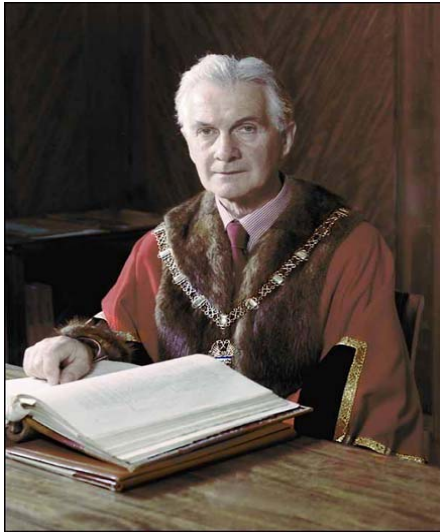
- Purposive – targeted
- Maximum variation
- Pre-selected criteria
- Saturation

Content of focus groups

- Spontaneous discussion
- Prompted discussion
- Use of imagery

Responses to focus group stimulus

Figure 1: Image of dignitary



Negative:

- Unhappy
- Ill
- No presence
- No sense of job

Positive:

- Power
- Success
- Educated
- Wealthy
- Elegant
- Mentally aware
- Dignified
- Cultured
- Healthy
- Secure
- Comfortable
- Command respect

Responses to focus group stimulus

Figure 2: Image of 'bag ladies'



Negative:

- Shocking image
- Poverty
- Homeless
- Too independent/stubborn
- Unhappy
- No family
- Need help/care
- Untidy appearance
- Psychological problems
- Lost self respect
- No dignity
- Degeneration

Positive:

- Companionship
- Good clothes
- Respect for each other
- Independent
- Happy
- Right to choose how to live

Analysis

- Focus groups tape recorded and transcribed verbatim
- Emerging themes identified and coded using Atlas.ti
- Comparison of coding of sample of transcripts
- Methods of analysis – constant comparison
- Thematic analysis carried out within three groups and then across three groups

Characteristics of older participants

Number of participants	72 (15 focus groups/2 interviews)		
Gender	57 female, 15 male		
Age	median age – 72. Range 50 – 90		
Marital status	31 – Widowed, 22 - Married, 5 - Divorced,		3 - Separated, 3 - Unmarried, 8 - Missing data
Education	10 - Degree 5 - A level, 32 - Missing data (unclear if missing data or no education)		13 - O level 13 - Certificate/diploma,
Location of current home	62 – Urban,	8 – Town	2 – Rural
Home circumstances	29 - live alone, 20 - live with spouse, 6 - residential care home,		6 – sheltered acc'dation (3 with spouse), 3 – live with other relatives, 8 - missing

Characteristics of professional participants

Number of participants	52 (12 focus groups)
Age	Range 18 -60
Gender	Female 44; Male 8.
Types of occupation	Care assistants: 11; Physiotherapy assistants: 8; Physiotherapists: 4; Nurses: 8; Occupational therapists: 5; Social workers: 3; Multidisciplinary rheumatology team: 4; Care home managers: 3; Geriatricians: 2; Medical students: 4.
Percentage of time spent with older people	Range 10 – 100 per cent; Mean 73 per cent.
Location of work	Hospital: 42; Residential homes: 7; Community: 3.

Characteristics of young and middle-aged participants

Number of participants	87 Young adults: 51 Middle-aged 36 (18 focus groups)
Gender	Young adults: 23 males 28 females Middle-aged adults: 9 males 27 females
Age	Young adults: Median age – 19.9. Range 16 - 30 Middle-aged adults: Median age – 51.8. Range 37 – 63
Marital status	3M-A – Widowed, 4 M-A – Separated/Divorced, 2Y; 28 M-A - Married, 48 Y: - Unmarried, 1 Y; 1M-A - Missing data
Education	13Y; 9 M-A - Degree 1Y; 9 M-A - O level 36Y; 7M-A - A level, 1Y; 11 M-A - Certificate/diploma,
Occupation	6Y; 11M-A Managerial/professional 2Y; 2M-A Intermediate occupations 2Y; 8M-A; Routine and semi-routine 2Y; 3M-A Manual 38Y (all students); 11M-A (4 students) Unemployed or never worked 2Y; Missing data
Location of current home	29Y; 19M-A – Urban, 15Y; 10 M-A – Town 7Y; 7M-A – Rural
Experience of caring for older people	37Y; 9M-A No experience of caring for older people 6Y; 14M-A Previous experience of caring for older people 4Y; 8M-A Currently involved in caring for older people 4Y; 5M-A Missing data

Salience of dignity

- How important is dignity for older people?
 - Concept seen as very important
- Problematic concept
 - Easier to talk about in its absence
 - Term ‘dignity’ problematic for some people
 - Respect - (*‘dignity, I think respect is better.’*)
 - Pride (*‘I think it should be ‘pride’ not ‘dignity’*)
 - Equality (*Dignity in my view is the acceptance of people in society on the basis of the equality*)

Nature and importance of dignity (1)

- Dignity is a universal/human value

65M: I've been trying to think of an all-embracing definition of dignity and it's very difficult. But the nearest I can think of is being treated with recognition of your rights as a human being.

M: Can I ask why you think rights are tied up with dignity?

65M: I think everybody is born with rights as a human being, even babies have got rights but I think that they become more important when you become more dependent on support.

(Group 15, Middle-aged adults).

Nature and importance of dignity (2)

- Minimum level of dignity

50Y: And I think you can be in the worst situation ever and still be dignified. It's like you're saying, you lose your dignity if you have to wear a nappy. I think people can still do that and be dignified. I think it's more about a feeling of yourself, almost an aura and I don't think it's necessarily the situation you're in or what you're subjected to. (Group 12Y, Young adults).

Nature and importance of dignity (3)

- Dignity as a statutory right

6M: I think dignity is something that we all should be given as a statutory right. Everybody should be allowed dignity. (Group 2M, Middle-aged adults).

Respect: self-respect and respect from others (1)

- Notions of self-respect and respect from others

87Y: I think perhaps there are two elements to it. There is perhaps how I think your personhood is perceived by others and I think with the term dignity you tend to associate an element of respect given to you. So I think that perhaps, in society that is the most important thing that we can think of. And there's also the level of personal dignity you know where how you feel about yourself and how you feel that you can fulfil certain roles. And I think for me it's a mixture of both of them. (Group 18Y, Young adults).

Respect: self-respect and respect from others (2)

- Professionals respect to clients

Pt 21: I think when you are ill, you are vulnerable anyway and I think hospitals, institutions whatever, can take away your self respect and esteem, take away your life really and I think by respecting people's wishes.... (Professionals, Nurses/HCAs).

Respect: self-respect and respect from others (3)

- Self-respect and dignity

Pt 17: I think this is up to the person themselves, if they lose, if they have lost their dignity within themselves and they no longer think that they are a person that matter... but I think if you tend to denigrate yourself and you think 'I am an old woman, it doesn't matter', then I think this is the downhill trend. (Older people, U3A).

Respect and identity (Self) (1)

Personal appearance

- Anonymity and old age

Pt 22: You get quite anonymous I think, you get grey hair and become anonymous. I don't know, but if there are a lot of young people, they tend to overlook you, they chat amongst themselves and they don't address you unless they want something. I think it's that sort of thing M: Do other people agree?

Pt 18: Yes, I think young people are in their little clique and even within the family you find that they will talk amongst themselves, and you think 'Well I am here as well?' (Older people, Luncheon Club).

Respect and identity (Self) (2)

Personal appearance

- Looking presentable/respectable

68M: Yes, but why should somebody who's always been conscious of their appearance have to change because they're no longer capable of doing it for themselves. If you're talking about dignity, the dignity for that person is to look neat. So if you take that away from them you're taking some of their dignity away. Your choices shouldn't change. If your choice is to wear a nice collar and tie and look smart well that ought to be your choice. Nobody should be able to take that away from you. That's when it destroys your dignity. (Group 15M, Middle aged adults).

Respect and identity (Self) (3)

Personhood

Pt 4: Yes, yes, that is the dignity, I don't want to, there's the indignity of losing one's mind and losing control over one's body, bodily functions, that is where you dignity comes in because it is undignified (Older people, Exercise Class).

Respect and identity (Self) (4)

Old age: a second childhood

Pt 1: A lot of elderly they go back to their childhood, so you have got to - in a way - treat them like children. I know it sounds horrible but you have got to try and treat them like a child

M: How would you do that?

Pt 1: I don't know, just...

Pt 2: It's the subject of their conversation. They will start talking about their parents. Most of the time, if you said 'Your parents are dead' they will hit you so you have to sort of say 'Where are they working?' or 'Maybe they had to work late' and you go along with it and then an hour later they might be back with you and not remember what they said, so you just have to go along with the flow. (Professionals, BUPA care assistants).

Respect and identity (interpersonal) (1)

- Politeness and good manners
 - But I think our youngest people are changing now. Because my husband has always opened doors for me but the girls in our society don't want that, they say, 'Do not patronise me'society is changing. So if the girls don't want that, the boys don't do it, and then perhaps if there was an older lady I would like to think my son would do that but I'm not sure that he would.... (Group 9M, Middle aged adults).

Respect and identity (interpersonal) (2)

- Communications

Pt 28: As people get older especially when they are in sort of hospitals or in residential homes and they're called by their Christian names, I don't think that's right.... Because especially our age group when we were either Mrs and Mr or something like that with respect... you did not call people Fred or Dolly.

Pt 24: And you waited didn't you for somebody to say 'Well my name is'....well you might know them a couple of years before you got round to Christian names. Now you go into hospital and the first day they say your Christian name (Older people, Health shop).

Respect and identity (interpersonal) (3)

- Older people as individuals: avoid stereotypes

Pt 44Y: I think it works both ways though like sometimes, older people don't respect younger people. You know they have this stereotype of what young people are like. When I was in school I was wearing my school uniform and I went into a shop and I said excuse me and everything to this old couple and they just started giving me a row because I had gone past them. I did say excuse me but because I was in my school uniform I think they just assumed that I was a rude young person. (Group 11Y, Young adults).

Autonomy and respect (1)

- Respect for identity related to autonomy

Pt 6M: There was no dignity in it, she could not get up, she had to be washed, bathed, she had to have everything done for her. Now a woman well over 80 who has done everything for herself her whole life, to be suddenly thrown into somewhere where she had to get it all done for her was just totally degrading.
(Group 2M, Middle aged adults).

Autonomy and respect (2)

Fear of being a 'burden'

- Pt 11: I remember thinking come what may, I will not do this to my own children, I won't be a liability to my children, if I can help it. (Older people, Sheltered home).
- Pt 17: Well they hounded me enough....not now....well they probably will pop up again some time but 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, patronising. (Older people, U3A).

Autonomy and respect (3)

The importance of 'choice'

Pt 4: I think one of the cruxes of dignity is that people do allow you to have your own freedom and choice.

Pt 5: And I think that's important, to make decisions for myself and not have other people make decisions for me because all of us want different things

Pt 3: They want you to do exactly what they want you to do and that is what I really object to...they are taking my choice away, they seem to want to take your choice away, they do not want you to have an opinion, they want to tell you 'You will wear pads', 'You will go to a day care centre', 'You will do and eat what we tell you'. (Older people, Luncheon Club).

Autonomy and respect (4)

Dilemmas for relatives

63M: Yes. I had a problem with this in the case of driving because my father carried on driving long after he was not safe on the road and all of us as a family kept dropping hints and trying in a nice way to say 'Perhaps its time to stop'. He just wouldn't accept it and I had to write to the DVLA and they organised a test for him and of course they took his licence off him because he was completely unable to cope. He was going across lights on red, stopping on green, drove up the footpath and this sort of thing. (Group 14M, Middle aged adults).

Autonomy and respect (5)

Independence and interference

9M: It was really quite a dangerous phase where she wanted to be much more independent than she was really capable of being. And it ended up, the classic thing that she fell in her kitchen and was there for 7 hours before her brother found her and you know, after that she had personal alarms and things but I've known other people's relatives the same. They have the personal alarms after they've had the accident and you know that was all about her independence, her dignity, her self-respect but almost clashing with her need for care and support (Group 3M, Middle aged adults).

Autonomy and respect (6)

Support without interference

Pt 39. Affording people choice and making sure that people are supported and given as much say in the way that they are supported. (Professionals, Social workers).

Social context and the experience of dignity (1)

Socio-cultural influences

- Inequality and social/economic position of older people

Pt 58: Pensions....we maintain that normal pensions are far too low. When we wrote to the MPs about this, the replies were most unsatisfactory and she used the demographic factor as the reason. So knowing that there is all this money not being spent, it's knowing that it's there....it just makes you feel useless and a burden doesn't it? (Older people, Older People's Forum).

Social context and the experience of dignity (2)

Socio-cultural influences

- Social exclusion and isolation

Pt 45: I think the worse thing is loneliness, that affects your dignity.

Pt 47: You can't be lonely in here, it's your fault if you are. If you choose to join in with other people you don't need to be lonely.

Pt 45: But they can't help it if they have got no family, they are bound to be lonely aren't they? (Older people, Nursing home).

Social context and the experience of dignity (3)

Socio-cultural influences

- Fear of violence

Pt 61: You can't socialise that much now, like walking by yourself to go to certain places because the older ones are being mugged by the young kids. So you are isolated and you stay in.

Yeah, we are vulnerable because we haven't got the strength and the capability. We have got to watch them.

Pt 64: You have to be worried about going home.

Pt 63: Even in the daytime you still have to be careful. The elderly are very vulnerable and it is scary. (Older people, Community Centre).

Social context and the experience of dignity (4)

Socio-cultural influences

- Employment – wrote off experience/skills

10M: But certainly, I mean there's so much experience out there that it's just wasted. (Group 3M, Middle aged adults).

Changes in the socio-cultural environment (1)

Rise of consumerism

Pt 29: I think we are all in a completely different culture now, before if people wanted something they worked for it, they saved for it, they respected it. I think now you buy something it breaks, you buy another one it does not matter...

Pt 28: Perhaps it has transferred onto people then as well...that when they get older, they are broken and then off they go to the scrape heap type of thing.

Pt 25: It's a throw away society. (Group 8M, Middle aged adults).

Changes in the socio-cultural environment (2)

Culture of 'youthfulness'

Pt 87: I think kind of culturally we're genuinely quite obsessed with youthfulness and I think there's a lot of that, that also leads on to the kind of specific roles for old people to play. They are victims of their age which leads to a kind of stereotype in a lot of people's minds. (Group 18Y, Young adults).

Changes in the socio-cultural environment (3)

Ageism

11Y: I think it's [society] surprisingly ageist and I think we tend not to notice it but you've only got to look at your average birthday card to see ageism everywhere. It's the butt of a lot of jokes and I don't know how many older people notice it and it's almost like sexism or the sort of mental illness stigma. It's all around you and I think probably certain people if you are not wealthy and haven't got so much freedom you might notice it much more. Where as if you've got your own social groups and your own friends you probably don't think of yourself as old because it doesn't affect you but I think it is there. Perhaps less so I don't know. (Group 4Y, Young adults).

The impact of health and social care services (1)

Unequal access to care

Pt:2 My doctor's locum is very disrespectful and I won't see him. He's cheeky. I just won't see him. I went to him, oh last year sometime with some complaint or other and he said 'Well what do you expect at your age?' And then further on in the conversation he said 'Well, you know, it's your age' and the third time he said it I said 'Stop talking about my age'.

Pt:1 Shocking.

Pt:2 So I won't see him any more. (Older people, Hospital).

The impact of health and social care services (2)

Lack of power/increased vulnerability

Pt 43: It's about people in hospital, 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.

Pt 38: I genuinely believe that young people have much more of a voice and are more willing to say or yell 'Nurse I need...' whatever. No, an older person doesn't do it, they won't cause problems. (Older people, Health Council).

Pt 36: I think people like patients to conform, I think it is easier if patients don't say very much, they just come in and it's almost like they don't even notice them. (Professionals, Rheumatology research team).

The impact of health and social care services (3)

Lack of continuity of care/staff commitment

Pt 21: Some of them are not committed, I sometimes wonder why they are doing the job, its probably lack of training because they get taken on by agencies and they may get training in how to make beds, how to wash somebody, I don't even think they do that actually.

Pt 24: They have got no idea about dignity. (Professionals, Nurses/HCAs).

The impact of health and social care services (4)

Reliance on routines

Pt 35: I told somebody off this week about it. One of the SHOs was standing in front of a patient and telling me something and trying to explain what had happened the week before and he said something along the lines 'Well you know, she is 89' in front of the patient as if that was an explanation of something and he said something else as well, essentially rude and treated the patient as if they were a cardboard cut-out. But I just said 'You cannot talk across patients like that and you cannot talk about them as if they are not there'. (Professionals, Geriatricians).

The impact of health and social care services (5)

Depersonalisation

6M: But the management don't realise. The management don't look at that person as a person. That person is a number or a sum of money coming in.

The impact of health and social care services (6)

Privacy

Pt 31: You can hear everything that is going on behind the curtains, when the doctors do the doctors round. All the other patients, unless of course you have got someone that is deaf, or if you have got someone who is deaf, you have to raise your voice so they can hear.

Pt 30: You say 'I am going to stand you up' as you have to explain everything so they know, and so you say 'I am just going to stand you up now and do your bottom', well of course that means that three people right next door can all hear.

Pt 33: Or 'Have you opened your bowels today'

Pt 30: Yeah, you have to ask that every day (Professionals. Nurses/HCAs).

The impact of health and social care services (7)

Managerialism

Pt 38: Its an interesting dichotomy because what you have got is a whole group of professionals who are trying their damndest to give people dignity and support and you have got a whole number of policies that are actually preventing you doing that, restricting you and we are working with these policies and juggling them (Professionals, Social workers).

Implications for policy

- Dignity a rich and salient concept for participants
- Dignity as identity and autonomy – challenge to ageism
- Appropriate resources for training of professionals and to ensure care standards are referred to
- Lack of justice in the allocation of goods and services to older people
- **Publications** : Woolhead G, Calnan M, Dieppe P, Tadd W (2004). Dignity in older age: What do older people in the UK think? *Age and Ageing* 33:(2), 165-170.
- Calnan, M. & Tadd, W (2005). Dignity and older Europeans: Methodology. *Quality in Ageing - Policy, practice and research*, 6:(1), 10-16.
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- Calnan, M., Badcott, D., & Woolhead, G (2006). Dignity under threat? A study of the experiences of older people in the United Kingdom, *International Journal of Health Services*, 36:(2), 355-375.