

## Maintaining Dignity in Later Life: a longitudinal qualitative study of older people's experiences of support and care.

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### In Brief

Dignity is a complex concept, understood in different ways and often most clearly when under threat. In later life health problems can be complex and life-threatening and lead to a loss of independence, identity and dignity. In these circumstances the support and care of others becomes crucial, increasingly so towards the end of life. This study explored the experiences of thirty-four older people whose health problems created a need for support and care.

We asked them about the changes occurring in their everyday lives and whether they felt the help they received promoted or undermined their dignity. Their accounts highlight the ways in which older people adapt to a growing need for help whilst also striving to maintain their independence. By focusing exclusively on their experiences and perspectives this study contributes to a fuller understanding of this final stage of the life course and how dignity can be maintained.

## Methods

The aim of this study was to examine preparations for the end of life made by older people with supportive care needs and the factors that support or undermine a sense of dignity.

Thirty-four participants aged 70 and over were recruited through GPs and day centres in Bristol and Nottingham. All lived at home and all had health problems that required support and care to varying degrees, including family care and support, medical treatment, community nursing and help in the home. Over the course of the study six men died, one woman was widowed, one separated from her husband and five moved to supported housing or a care home. All had capacity to consent to participate throughout the study.

Table 1 Participant characteristics at the beginning of study

34 participants	
Male	21
Female	13
Aged 70–79	6
80–89	26
90+	2
Living alone	15
Living with partner	19
Have children living	26
Home owned	27
Home rented	7

Participants were interviewed several times over the period between June 2008 and December 2010. Most were seen four times, some five times, and all were contacted by telephone as well. Interviews were recorded and transcribed. At each point of contact we encouraged participants to talk about things that had happened in the period since the last contact.

The first interviews focused on participants' everyday life, their experiences of being helped and their views about ageing and dignity. The second focused on their earlier life, including childhood, work, marriage and family life. The third focused on changes in participants' circumstances since the first interview and the fourth reviewed and expanded on what participants had talked about previously. Nine participants were seen for a fifth time to focus on particular events they were experiencing at that time.

At the end of the project two social events were organised at which we presented our findings and gave each participant a project report. These were attended by 17 participants, together with family members and friends, giving us the opportunity to thank them and to check out their views of the findings. The feedback was very positive and supportive. Several people told us that participating in the study had been interesting, stimulating, helpful and enjoyable.

## Summary of key findings

### 'Old age is sprung on us, isn't it'

Participants often expressed surprise about the circumstances they found themselves in. Most regarded the onset of illness as the point at which they started to feel old and life had begun to be less predictable. Their illnesses were not unusual for this

age group. They included cancer, heart problems, emphysema, stroke, diabetes, osteoporosis, arthritis and cataracts. Several had falls both before and during the course of the study. Participants talked about the loss of mobility, strength and confidence that their illnesses had caused and about the loss of activities that had been a major part of their lives. These included driving, gardening, dancing, golf, walking, knitting, cooking, decorating and home improvements.

These changes were highly significant to participants' sense of self. 'I used to go anywhere and everywhere but I feel like a fish out of water now', said Rose. This sense of dislocation put participants under considerable pressure to adjust their whole way of life. Mary summed up what many told us when she said: 'Inside I feel as though I ought to be able to do things, quite active. But I'm not and it's hard to accept.' Some participants reflected on their past, seeking reasons to be positive. Frederick said; 'I try to be as philosophical as I can. It's difficult sometimes but there we are... I've had a good life, when I look back, I really have.' By contrast, a small number had unresolved problems from earlier life, which still caused them a great deal of anguish.

### The need for perseverance

Focusing on the day-to-day, participants viewed their struggles with illness and increasing disability as a fact of life that required a great deal of perseverance to deal with. Finding new activities or adapting old activities important. Several learnt to use computers and others took art classes at day centres. Mobility aids, such as electric scooters, were seen as ideal for those who wanted to go to the shops rather than buy on-line, although others regarded mobility aids as undignified. All made great efforts to maintain their health as much as possible in the following ways:

- **Prevention:** eating well, taking vitamins and supplements, getting out of the house and staying active through physical exercise as well as reading and doing puzzles to stay mentally alert.
- **Monitoring:** regular appointments at hospital outpatients and GPs for flu jabs, check ups and tests on blood, urine, stools, blood-pressure, eyes, ears and heart rate. These visits were often complicated by transport problems.
- **Individual management of illness:** including stoma care and management of continence problems, managing medication and monitoring its side effects, learning to use aids and home adaptations and finding new ways of doing familiar things. For example, James, who had Parkinson's disease, learnt to stir his tea from the shoulder rather than the wrist because this was steadier.

These activities add up to a significant amount of physical, mental and emotional effort and demonstrate that despite their loss of health most participants remained active and retained agency over their lives.

### Holding on to independence and accepting help: a difficult balance

Not surprisingly, the loss of independence or self-reliance was hard for participants to accept and was seen by most as inevitably leading to a loss of dignity. Jonathon said that his

dignity had *'gone down below ground level'* since he became dependent on his wife. Participants differed in how they felt independence could be maintained. Whilst some thought it best to have help from family members others preferred to pay for services. Being as self-reliant as possible was widely regarded as a moral obligation, although participants acknowledged that it was possible to overdo it. Peter said: *'I suppose we're independent to the point of being daft about it.'* It was also important therefore to be 'sensible' and accept help when necessary.

Not wanting to be a burden but having to accept a growing reliance on others was the complex task that participants faced and their identity and dignity were bound up in this task. Some struggled as much as possible without seeking help. Lena said she felt that asking for help was *'giving in'*, as opposed to *'fighting it'*. Asking for help was more acceptable in some circumstances than others and a 'proper reason' needed to be given. A proper reason would include illness, particularly at times of treatment or when help was needed with particular jobs – typically 'heavy' things such as gardening and shopping. Older people's social status was an important factor in understanding fears about burdensomeness. Most opted for surgery and other treatment, in the interests of restoring health and mobility but there were several references to the cost. When Ruth (aged 88) was advised by her doctor to have surgery she said *'I don't want money wasted on me, because it is a waste isn't it, at my age?'*

### A precarious life: facing the future

Participants frequently spoke in terms that reflected the shifting and precarious nature of life. Typical expressions were; *'At the moment I'm still able to cook my own food'* and *'As long as we're able to manage, we'll stay living where we are'*. These expressions convey the instability of their current circumstances and the prospect of further change ahead. Staying positive was an important aim but participants realised the significance of change at this stage of life and the growing nearness of death. Peter, for example, said:

*'I'm living on bonus time... according to the law of averages I'm not long for this planet... The things I could do I know I can't now. We've just had this house painted because it's no good getting the ladders out. I can't run up and down ladders now.'*

Participants did not find it easy to talk about the future or about the end of life. Those who had money or property had made wills and some had made funeral plans. Ten had discussed their end-of-life treatment preferences with doctors, solicitors, family or close friends. Six had made formal arrangements for lasting power of attorney. Significantly, some had made a decision not to accept treatment knowing that this might hasten their death and such decisions can be understood as exercising choice at the end of life. Others thought that planning ahead was pointless, because there was no control over the future. A small number talked about their desire to 'end it all' because they were exhausted and saw no point in their lives. James thought that he was getting closer to the point where he would want to *'check out'* and, like others, wished that this could be made possible through the health service.

### Networks of support: the importance of family and friends

Whilst a few participants were isolated the majority were very much involved in family life and had contact with friends and neighbours. Family support was not all one-way - providing financial help to children and grandchildren was common. Help from family or friends confirmed to participants that they had someone to care about them and was important when making decisions, such as whether or not to move or have the house adapted. Such decisions were easier when talked through with somebody who cared, even if there was disagreement about the best way forward. Some described how being 'too independent' could cause a worry to families. Brenda went into a care home, partly to avoid being a burden to her daughter. Her physical and mental health improved subsequently as her anxieties about living independently were resolved.

### Dignity and indignity in health and social care

Needing help from strangers with personal, bodily care was often dreaded: *'The very thought of having somebody washing me, you know'*, said May. Most found that personal care was not as bad in reality as they had expected but this depended on how the help was given. Jane was upset when she was watched by a group of trainees as she was strip-washed in hospital. Most participants were satisfied 'on the whole' with the way they were treated by health and social services but 22 related specific instances where they had been on the receiving end of neglectful, hurtful or offensive behaviour by staff. They talked about rude and arrogant doctors, hospital nurses who ignored calls for help, thoughtless receptionists who forgot about them in waiting rooms and inefficient administration. James was laughed at when he questioned whether he should take medication that could make him sexually impotent whilst Frederick was told *'You're not very bright, are you'* by an eye specialist when he became confused at his appointment. A common concern was that it was all too easy to become a number in the system but when participants encountered staff that made an effort to listen and understand their self-esteem was boosted greatly. What they said they appreciated were:

- Awareness by others of a need for help.
- Being offered help without having to ask
- Awareness of the impact of illness on the person and their sense of who they are
- Acts of kindness and thoughtful gestures
- Respectful attitudes and courteousness
- Being treated as an intelligent person with a part to play in treatment and care
- Being treated as an individual with their own history, preferences, fears and beliefs
- Being helped at the right pace. Not going too fast
- Having someone help you make difficult decisions – with honesty and respect

## Conclusion

The findings from this study reinforce the need for a better understanding of older people's perspectives on this final stage of the life course. Our participants have revealed how complex and demanding a time this is - physically, mentally and emotionally – as they described how they came to terms with bodies that no longer enabled them to live as they were accustomed to living. All participants talked about the challenges their health problems posed to their sense of self and their identity. Without exception they worked extremely hard to maintain their health and independence whilst at the same time coming to terms with their growing dependency on others. This was a difficult task and although they faced many challenges in common, they differed in terms of their resources, relationships and capacity to persevere with it. Their accounts demonstrate how easily a sense of dignity can be lost as familiar ways of life are eroded by illness and disability. The evidence is clear that thoughtless and unkind behaviour exacerbates this loss of dignity and sense of self whilst sympathetic and respectful care can help to maintain it. Being given support in making decisions and being enabled to find their own ways of coming to terms with changes in their lives restored participants' feeling that they mattered as individuals with dignity.



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