Living and dying with dignity: a qualitative study of the views of older people in nursing homes

SUE HALL, SUSAN LONGHURST, IRENE HIGGINSON

King’s College London, Department of Palliative Care, Policy and Rehabilitation, London, UK

Address correspondence to: S. Hall. Tel: (+44) 207848 5578; Fax: (+44) 207848 5517. Email: sue.hall@kcl.ac.uk

Abstract

Background: most older people living in nursing homes die there. An empirically based model of dignity has been developed, which forms the basis of a brief psychotherapy to help promote dignity and reduce distress at the end of life.

Objective: to explore the generalisability of the dignity model to older people in nursing homes.

Methods: qualitative interviews were used to explore views on maintaining dignity of 18 residents of nursing homes. A qualitative descriptive approach was used. The analysis was both deductive (arising from the dignity model) and inductive (arising from participants’ views).

Results: the main categories of the dignity model were broadly supported: illness-related concerns, social aspects of the illness experience and dignity conserving repertoire. However, subthemes relating to death were not supported and two new themes emerged. Some residents saw their symptoms and loss of function as due to old age rather than illness. Although residents did not appear to experience distress due to thoughts of impending death, they were distressed by the multiple losses they had experienced.

Conclusions: these findings add to our understanding of the concerns of older people in care homes on maintaining dignity and suggest that dignity therapy may bolster their sense of dignity.

Keywords: aged, nursing homes, qualitative research, dignity, elderly

Introduction

The majority of residents in nursing homes die within 2 years from multiple medical pathologies [1]. They are often heavily reliant on staff for their care, which can erode their sense of dignity. Maintaining dignity is given a high priority in health and social care strategy documents in most European countries and particular concerns have been raised about loss of dignity in care [2]. Although there is a great deal of rhetoric around dignity, there is no agreed definition [3]. A brief review of the studies exploring the concept of dignity from a nursing perspective showed a wide range of definitions and themes relating to the construct; however, a common theme was respecting a patient as a person [4]. Two
studies have explored the views on dignity of older people in care homes. One [5] found that not being a burden was important to residents, and their sense of dignity was threatened by illness and care needs, the other [4] described three main themes: (i) the unrecognisable body; (ii) fragility and dependence and (iii) inner strength and a sense of coherence. Further information on these is given in Appendix I in the supplementary data available at Age and Ageing online.

One approach to dignity-oriented care provision, which focuses specifically on end of life, is Chochinov’s dignity-conserving model [6]. The model was developed from interviews with patients with advanced cancer (average age 69 years), focussing on what supports and what undermines their dignity. The model comprises three major categories: (i) illness-related concerns; (ii) dignity conserving repertoire; and (iii) social aspects of the illness experience. Each of these categories has themes and subthemes (Box 1). These are described in more detail in the results section of this paper.

A particularly important aspect of Chochinov’s dignity model is that it has provided the framework for psychotherapy to help promote a sense of dignity and reduce psychological and spiritual distress for people reaching the end of life [7]. Piloting has shown promising results for people with advanced cancer [7] and their families [8]. It is clear from previous studies [4, 5] that older people living in care homes are vulnerable to having a fractured sense of dignity, which suggests that dignity therapy may be of benefit to them. Since the therapy is brief (usually only two sessions) and can be delivered at the bedside by a trained health care professional, it may be feasible to offer this in a care home setting. However, the dignity model, and therefore dignity therapy, is based on the views of people with cancer in Canada, most of whom were cared for in the community. Less than 10% of residents of nursing homes die from diagnosed cancer [1]. Whether or not the model is generalisable to people with non-cancer, or to those living in other settings such as care homes, is not known. The aim of this study is to explore the generalisability of Chochinov’s dignity model to older people cared for in nursing homes.

**Methods**

**Design**

Since the aim of this study was to explore an existing theoretical model, it was not highly interpretive; consequently we used a basic qualitative descriptive approach [9].

**Setting and participants**

The sample comprised 18/86 (21%) older people living in one of two care homes with nursing in London. The inclusion criteria for the study were as follows: aged 75 and over and being able to speak English. The exclusion criteria were being unable to provide informed consent, or too ill or distressed to take part. Managers excluded 23 residents, 39 residents did not return reply slips and 6 we felt were unable to understand their participation in the study.

**The interviews**

Interviews were recorded and transcribed verbatim. The main questions were those used in the study to develop the dignity model [6].

**Analysis**

Qualitative content analysis was used, which is appropriate for our descriptive approach [9]. Since the aim of this study was to explore the generalisability of this model to a different population, the analysis was largely deductive: we started with a framework with this model as a priori themes. The initial framework was then modified to exclude any themes not supported by residents’ accounts and to capture new emergent themes. To address issues of rigour and trustworthiness, the coding framework was agreed by SH and SL. We also paid attention to deviant cases. Themes are shown in Box 1 and quotes supporting these are shown in Box 2.

**Results**

Characteristics of the 18 residents are shown in Table 1. Only one had been diagnosed with cancer (non-metastatic).

Although most of the themes in Chochinov’s dignity model were supported, we found no evidence of the themes
Box 2. Quotes from residents

Illness-related concerns

1. Sara: I can’t get in the bath, so they wash me down every morning in here . . . . . I’ve got no choice darling, have I? . . . . . I tried to get in the shower but I can’t do it, my breathing won’t let me . . . . I have to sit on the commode cos I can’t get to the toilet. That to me is embarrassing but you’ve got to accept it.

2. Molly: your brain starts doing things it shouldn’t . . . . it never used to worry me at all.

3. Grace: The thing is I’m fortunate enough that I haven’t lost me marbles yet (laughs) YET . . .

4. Grace: If you’re very ill, I, when I first went into [name of hospital] I used to pray that I would die . . . . I felt so ill. But as I got better and better I don’t wanna go now (laughs) . . . . I’ve got a lot to live for with all the family.

5. Anne: Now I’m a bit like that, apprehensive about doctors, cos they can be very wrong sometimes . . . . I wonder why people of our age have to have these things [strokes].

6. Sara: Well I hope to be here till I die (laughs) . . . . Yeah, as long as I don’t have to go back in hospital. They know that. So I’m going to die in this chair or on that bed (Sara died in her bed within six months of being interviewed).

7. Jack: I’m not ill . . . . I am now very old, and I definitely need some nursing care (at the time of the interview Jack, who had severe arthritis, had not left his bed for some time and was heavily reliant on staff for all his care needs. He died the day after the interview).

8. Trudy: It broke my heart everything went, I've got no home to go back to. So you might as well say I'm here forever . . . . Well I do get upset, I do think about my home, you know, and I've lost one or two of my friends . . . .

Dignity conserving repertoire

9. Anne: When you lose your pride I think, well they say you’ve lost your dignity, and that’s how I think it is. It is pride. A feeling, an emotion, you think where they should not have disturbed you or broken in on your, where you are, cos you are there.

10. Jack: Christian, military, dignity . . . . I am fond of speaking about these things. It's a pleasure for me, this is my dignity . . . . I value my dignity. I display my dignity wherever I am . . .

11. Ellie: I don’t expect to be valued at my age, after all I’m eighty-eight or eighty-seven.

12. Anne: I miss my routine . . . . in the morning I get up very early, I don’t have to but I’ve always been an early riser, even as a child and I’m up about a quarter to six and I go in to the bathroom, have my wash and that, and I always like to think, when I did it at home, put the kettle on, have a cup of tea and that first morning cup of tea . . . .

Social dignity inventory

13. Sara: If they’re going to do something personal they always close the door and they always knock before they come in.

14. Julia: I have a young man who comes here most mornings and dresses me and he has to wash me and you know he’s very nice but I’m lying there and think my God I never thought I’d come to this, a young man washing my private parts.

Illness-related concerns

There are two main themes in this category: level of independence and symptom distress. Residents felt a loss of independence in a range of domains, including their financial affairs, personal care and their social lives. We found evidence to support both of Chochinov’s subthemes of level of independence: functional capacity and cognitive acuity. The theme functional capacity was particularly strong and concerned many current activities of daily living, including, being unable to walk, go out alone, take their medication, bath, dress, eat and enjoy hobbies. For example, Sara describes her embarrassment when being helped with washing and using the commode and how she would rather die than be more dependent (Quote-1). Only Molly (who had no recorded cognitive problems) expressed concerns about cognitive acuity (Quote-2). In contrast, others were proud that they had kept these abilities (Quote-3).

Symptom distress includes two subthemes: physical distress and psychological distress. In his study to develop the dignity model, Chochinov describes symptoms of people with cancer that were so severe that people had felt that death is the only option [6]. The residents in our study reported many symptoms including pain, breathlessness, loss of appetite, vomiting, bladder and bowel problems and sensory losses; however, none described these as so severe at present that they had lost the will to live. Grace describes how successfully managing such symptoms increased her feelings of hopefulness and will to live (Quote-4).

There are two subthemes to psychological distress: medical uncertainty and death anxiety. Medical uncertainty focuses any concerns that people may have regarding their lack of knowledge about their current health status or treatment. Only Anne

Table 1. Characteristics of participants

<table>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
<th>Barthel score</th>
<th>Karnofsky score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Norma</td>
<td>98</td>
<td>85</td>
<td>60</td>
</tr>
<tr>
<td>Sadie</td>
<td>93</td>
<td>10</td>
<td>30</td>
</tr>
<tr>
<td>Pat</td>
<td>82</td>
<td>5</td>
<td>30</td>
</tr>
<tr>
<td>Mary</td>
<td>88</td>
<td>35</td>
<td>40</td>
</tr>
<tr>
<td>Anne</td>
<td>84</td>
<td>90</td>
<td>60</td>
</tr>
<tr>
<td>Amy</td>
<td>85</td>
<td>0</td>
<td>30</td>
</tr>
<tr>
<td>Fran</td>
<td>80</td>
<td>5</td>
<td>30</td>
</tr>
<tr>
<td>Ellie</td>
<td>88</td>
<td>50</td>
<td>50</td>
</tr>
<tr>
<td>Hope</td>
<td>81</td>
<td>15</td>
<td>40</td>
</tr>
<tr>
<td>Sara</td>
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<td>35</td>
<td>50</td>
</tr>
<tr>
<td>Trudy</td>
<td>83</td>
<td>40</td>
<td>50</td>
</tr>
<tr>
<td>Betty</td>
<td>94</td>
<td>10</td>
<td>40</td>
</tr>
<tr>
<td>Jack</td>
<td>85</td>
<td>10</td>
<td>30</td>
</tr>
<tr>
<td>Diana</td>
<td>92</td>
<td>55</td>
<td>50</td>
</tr>
<tr>
<td>Grace</td>
<td>90</td>
<td>35</td>
<td>40</td>
</tr>
<tr>
<td>Molly</td>
<td>91</td>
<td>50</td>
<td>50</td>
</tr>
<tr>
<td>Julia</td>
<td>84</td>
<td>40</td>
<td>40</td>
</tr>
<tr>
<td>Rita</td>
<td>78</td>
<td>45</td>
<td>50</td>
</tr>
</tbody>
</table>

*Names have been changed to protect confidentiality.

Assesses ability to perform activities of daily living: 0 = total dependence − 100 = maximum independence.

Assesses performance status: 0 = death − 100 = perfect health.

*Afro Caribbean. All other participants were White British.
expressed concern about these issues (Quote-5). Death anxiety reflects severe anxiety about the process of, or anticipation of, dying. No resident in our study showed any distress at the thought of dying. Death was rarely mentioned at all, and when it was, residents usually joked about it (Quote-6).

Old age is not an illness is an emergent theme in our study. Although not strictly an illness-related ‘concern’, this theme fits best in this category. Not only did some of the residents show little anxiety about impending death, they saw their symptoms and loss of function as due to old age rather than illness (Quote-7). Feelings of loss is another emergent theme in our study. Although residents did not appear to suffer from distress due to medical uncertainty or impending death, they reported distress in other domains, particularly the important and often multiple losses most of them had experienced: home, family, friends, important roles, function and independence, freedom and future (Quote-8).

Dignity conserving repertoire
This category comprises two subthemes: dignity conserving perspectives and dignity conserving practices. Dignity conserving perspectives are personal characteristics which help buffer the impact of progressing illness on a person’s sense of dignity. We found support for all but one of the eight dignity conserving subthemes. In view of their loss of function and independence, maintenance of pride can be difficult for residents. However, as shown in other themes, residents were proud that they had kept their cognitive abilities, some independence and valued roles. Anne talks of the link between pride and dignity and how respect of personal privacy can be crucial to this (Quote-9). For Jack, pride, and therefore dignity, was something deep inside him, and it remained intact despite his decline in functioning and reliance on care home staff (Quote-10). In contrast, Ellie describes how, as an older person, she felt she was no longer of value (Quote-11). Generativity/legacy refers to the need to leave behind something lasting after death. Although identifying their accomplishments and contributions was important to some of the people with cancer in Chochinov’s study, none of the residents in our study raised concerns about leaving behind a legacy, possibly because their concerns focussed on no longer being able to make a contribution now, rather than on their death and on what they may or may not leave behind. Remaining subthemes are given in Appendix II in the supplementary data available at Age and Ageing online.

Dignity conserving practices are actual techniques; however, it is often difficult to differentiate these from the enduring characteristics which are a defining feature of dignity conserving perspectives. There are three subthemes in Chochinov’s dignity model (i) living for the moment; (ii) maintaining normalcy; and (iii) seeking spiritual comfort. Overall, these were not strong in our study, particularly living for the moment and seeking spiritual comfort. Maintaining normalcy involves carrying on familiar routines in the face of the challenges imposed by declining health. The scope for doing this in a care home environment is limited, particularly for residents with severe loss of function. Some clearly missed being able to follow their normal routines, but had managed to maintain at least some sense of normalcy (Quote-12). Remaining subthemes are given in Appendix III in the supplementary data available at Age and Ageing online.

Social Dignity Inventory
This category focuses on social concerns or relationship dynamics which can erode or bolster a person’s sense of dignity. There are five subthemes (i) privacy boundaries, (ii) social support, (iii) care tenor, (iv) burden to others and (v) aftermath concerns. Privacy boundaries reflect intrusions into an individual’s personal space when receiving care. Although staff generally respected residents’ need for privacy (Quote-13), there were incidents where lack of privacy undermined a sense of dignity. Residents who depended on staff for most of their personal care felt they had to resign themselves to the inevitable loss of privacy, and female residents sometimes felt uncomfortable when male carers attended to their personal care (Quote-14). Aftermath concerns are worries or fears about any problems their death might cause to those they leave behind. Residents in our study expressed no aftermath concerns during their interview, possibly because death was not at the forefront of their minds. Remaining subthemes are given in Appendix IV in the supplementary data available at Age and Ageing online.

Discussion
This study of the views of older people reaching the end of life in care homes in the UK, which is the first to examine the generalisability of Chochinov’s dignity model to another context, broadly supported the three main categories of the model. However, some felt their symptoms were due to old age rather than illness, and although residents did not appear to be distressed by thoughts of death, some were distressed by the many losses they had experienced.

Although only one of the participants in our study had been diagnosed with cancer, many of their illness-related concerns were similar to those described by people with advanced cancer [6]. Loss of physical functioning resulted in loss of independence and dignity. The importance of maintaining functioning and independence in fostering a sense of dignity is acknowledged in other models of dignity [10, 11], and worries about becoming demented and/or completely physically dependent [10, 11] and fears about possible increased dependence [4] have been shown in other studies focussing on older people.

Although residents described a range of physical symptoms, none were reported as severe. It is possible that some experienced more severe symptoms but did not feel that they had an impact on their sense of dignity, and it is likely that residents experiencing more severe problems did not take part in the study. Some challenged the word ‘illness’ as they saw their symptoms and loss of function as a natural part of the ageing process rather than due to illness, a view supported
by research showing that only 9% of people in care homes die of a recognisable terminal illness [1].

Although residents did not seem to be distressed by medical uncertainty or thoughts of death, some were distressed by the major and often multiple losses they had experienced. In addition to loss of function and independence, most had outlived their partners and many of their friends. Some had outlived their children. All had lost their homes and most of their personal possessions. Such losses were not captured in the Chochinov’s dignity model, probably because most of the participants in his study were being cared for at home. The importance of considering the role of loss in maintaining dignity for older people in care homes is supported by other studies [4, 10]. Interventions addressing psychological distress associated with such losses are likely to help promote a sense of dignity.

Themes relating to the social aspects of the illness experience were similar to those of the people with advanced cancer in Chochinov’s study [6]. There is a great deal of emphasis on protecting the privacy of patients to maintain dignity in care [2], and other studies have highlighted the importance of privacy in fostering a sense of dignity [3, 12]. Concerns about having intimate aspects of personal care performed by male carers, which have been reported in other research [10], are more of a challenge, since most residents of care homes are women and many care assistants are men.

In view of their dependence on care home staff for most aspects of their lives, it is not surprising that perceptions of attitudes of care home staff impacted residents’ sense of dignity. Care tenor was linked to other dignity themes, for example, attitudes that foster dignity are reflected when care home staff encourage independence, respect privacy, provide social support and care in such a way that residents maintain a sense of pride and do not feel that they are a burden. We found no evidence of aftermath concerns in our study. Again this might be due to the age of our participants. The quote supporting this theme in Chochinov’s model [6] was from a patient with young children. Although some residents had adult children and grandchildren, they no longer had responsibility for their care.

Dignity conserving perspectives are based on enduring characteristics or world views. There are elements of these themes in other models or definitions of dignity. For example, feeling that one essence remains intact and still being worthy of being treated with respect are the major components of ‘continuity of self’. A common theme from Franklin’s review of the dignity construct was ‘respecting the patient as a person’ [4], and ‘respect and recognition’ was a major theme in the Older European Study [10]. Furthermore, dignity conserving repertoire has much in common with the coping strategies which people use when faced by illness and other traumatic events [13].

A limitation of this study is that it reflects the views of a small proportion of the residents in each care home: those who were willing and able to take part in the study. Only one of our participants was non-white and only one was male. It is possible that there are cultural or gender differences in resident’s views on dignity and how to maintain it. Further studies are needed to explore the generalisability of our findings to these and other groups of older people.

Conclusions

Our findings add to our understanding of the concerns of older people living in care homes on maintaining dignity and demonstrate the utility of the dignity model in a new context. Clearly, care home staff can do a great deal to help residents maintain dignity; however, many of the concerns expressed by our participants were due to inevitable losses. Dignity psychotherapy has been developed to address such concerns [7]. However, it is also important to focus on the attitudes of staff towards residents. Documents similar to those produced during dignity therapy may help staff achieve this.

Key points

- The views of older people in care homes on maintaining dignity at the end of life were broadly similar to those of people with advanced cancer.
- In contrast to the cancer patients, the residents in our study did not express concerns about death; however, some were distressed by the multiple losses they had experienced.
- Interventions such as dignity therapy are needed to help bolster a sense of dignity and reduce psychological distress in older people in care homes.

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Conflicts of interest

No conflicts of interest.

Declaration of sources of Funding

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Ethical approval

King’s College Hospital Research Ethics Committee (07/Q0703/22).
Supplementary data

Supplementary data are available at Age and Ageing online.

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