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**ENLWD01 Living well with
Dementia Project**

Living well with dementia: enhancing dignity and quality of life, using a novel intervention, Dignity Therapy

Institutions involved: University of Nottingham; NHS Tayside, NHS Grampian



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i. Acknowledgments

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1. Summary & keywords

Dementia is a syndrome which can have a number of causes that lead to a progressive decline in multiple areas of functioning. The maintenance of dignity and enhancement of quality of life are key, integral elements of care. Meaningful communication with people who have dementia becomes more difficult as the condition progresses. Improvements to communication may have a positive effect on the person's quality of life, with individualised approaches being strengthened by the use of existing strategies such as memory/life story approaches.

Dignity Therapy is a short psychotherapeutic intervention that uses a trained therapist to take the person through a recorded, guided interview process, to produce a generativity document that creates a lasting, written legacy. Dignity Therapy may provide an opportunity for individuals to begin advance care planning during a time when they are still able to communicate well, thereby engendering a sense of meaning and purpose. The aim of this study was to assess the feasibility, acceptability and potential effectiveness of (modified) Dignity Therapy to improve the quality of life and reduce psychological and spiritual distress in older individuals with early stage dementia.

Key words: Dementia, dignity, quality of life

2. Background

Dementia is a syndrome which can have a number of causes that lead to a progressive decline in multiple areas of functioning (DoH 2009). The average duration of dementia can

be between 7 – 12 years with a loss of ability to communicate meaningfully emerging during this time while unique, individual qualities remain (Scott 2013). Dementia has been recognised as being a palliative condition (van der Steen et al 2013). The maintenance of dignity and enhancement of quality of life are key, integral elements of care and feature prominently within the National Dementia Strategy (Manthorpe et al 2010; Scottish Government 2012).

Realisation of the importance, both politically (Department of Health 2012; Scottish Government 2013; G8 summit report 2013) and sociologically (Brooker 2004; Sabat 2001), of dementia research in all settings is growing; however, despite this, UK Government spending on dementia research is still considerably less than other major disease areas such as cancer and heart disease (Alzheimer's Research UK 2013). Research is also a priority for people affected by dementia: when asked about what motivates people to participate in dementia research, people with dementia and their carers expressed the view that not participating in dementia research was a form of deprivation. They felt that the opportunity to participate in research should be offered to all people with dementia (Law et al 2013).

Despite the importance attached to the enhancement of dignity and quality of life, it has been recognised that less attention has been paid to the dignity-related concerns of older, frail individuals who are not yet dying and find themselves outwith palliative care settings (Chochinov et al 2012). The particular features of quality of life that are mentioned by individuals with dementia include feeling accepted for who they are, being understood, and enhancing meaning in life (Dröes et al 2006). Ryan et al (2009) propose that biographical awareness may well be able to influence the care environment.

It is also recognised that meaningful communication with people who have dementia becomes more difficult as the condition progresses and that carers seek ways of improving their own communication abilities with the person with dementia (Bleathman and Morton 1996). While it is important to involve the person with dementia in their care, the challenge remains how to achieve this when capacity is lost. Improvements to communication may

have a positive effect on the person's quality of life, with individualised approaches being strengthened by the use of existing strategies such as memory/life story approaches (de Vries 2013).

One approach to the involvement of people with dementia when they are cognitively able is the use of advance care planning. Sampson et al (2010) define this as a discursive process that incorporates important values as well as goals, care preferences and future wishes. However, it has been acknowledged that this may be challenging to achieve due to the sensitive nature of the discussions (Chang and Pang 2010). The early diagnosis of dementia and post-diagnostic support includes attention to the creation of patient-centred support planning using such approaches as the 'Getting to Know Me' document (Alzheimer Scotland 2013).

Taking these issues into consideration, there are nevertheless issues regarding participation in research, particularly for those who do not have a voice, because of their communication difficulties, cognitive abilities, and the perception of others that their voice does not count (Brooker et al 2011). For this study, therefore, it was hypothesised that such issues could be addressed by the use of Dignity Therapy as a means to provide an opportunity for individuals to begin their advance care planning.

The aim of Dignity Therapy was originally to engender a sense of meaning and purpose for people approaching the end of their life (Chochinov et al 2005). It is a short psychotherapeutic intervention that uses a trained therapist to take the person through a recorded, guided interview that is then transcribed and edited. The written, edited version of the interview is read aloud to the person and then given to them in a final document. The idea of this document is that it creates a lasting, written legacy called a generativity document. It does have similarities to life story and reminiscence therapy in that it focuses on the improvement of the person's sense of wellbeing (Simpson et al 2004); however, Dignity Therapy does not aim to record every element of a person's life.

Dignity Therapy has been carried out with people at the end of their lives with the reported benefits of increasing a sense of dignity, improving quality of life and being of help to families (Chochinov et al 2011). It has also been carried out in a feasibility study with individuals who have motor neurone disease (Bentley et al 2014), with nursing home residents without cognitive impairment (Hall et al 2012a) with good self-reported benefits. In addition, Chochinov et al (2012) studied the use of Dignity Therapy for people in care homes without cognitive impairment, and with proxies speaking on behalf of people with cognitive impairment. However, this latter approach did result in differences in the content of the Dignity Therapy documents and indicates the importance of the person themselves being involved in the process.

Dignity Therapy may have a role in gathering the thoughts of people with dementia to have as a legacy. Family members who received the Dignity Therapy documents reported finding out information about the person that was unknown, which prompted further discussion (Goddard et al 2013a). Staff working in hospice environments where Dignity Therapy has been used reported their belief that the Dignity Therapy document would have future benefits for families (Montross et al 2013). Moreover, in a follow-up study of bereaved families, McClement et al (2007) found that the Dignity Therapy document was a source of ongoing comfort in their grief.

Dignity Therapy can also give care staff an opportunity to understand the person at a time when they can no longer communicate and potentially increase connections with patients (Montross et al 2013). This may help to respect the individuality of the person with dementia (Chochinov et al 2012) and provide important insights (Alzheimer's Society 2012, 2014).

However, Dignity Therapy is not usually carried out with people who have cognitive impairment. Hall et al (2012b) report that it is not recommended for such people due to memory distortion and the potential for distress. Hall et al (2012b) also noted that Dignity Therapy took longer to complete than anticipated.

Modification of Dignity Therapy

Our feasibility study aimed to discover if a modified approach to Dignity Therapy could be beneficial to individuals with newly diagnosed dementia and their families. We anticipated that it would allow the person to create a permanent record of themselves as a person and who they really are. This could have profound implications for the person with dementia in terms of their quality of life, as well as health professionals caring for that person, particularly in terms of person centred care, compassion and empathy. It would also give the person's friends and family a permanent record of that person and their wishes and dreams, whilst their cognitive state was still intact. This could be likened to creating a person centred 'time capsule'.

To agree the modification of Dignity Therapy we commenced the project in August 2013 with a 2 day workshop in Dundee Scotland. The workshop was facilitated by BJ. Attendees were the project team/steering group, four people affected by dementia (two patients and their spouses, who attended for day 2) and Professor Chochinov, the developer of Dignity Therapy from Canada. The workshop was extremely successful and allowed us to make the decision that the question format of the original Dignity Therapy question format would be adhered to for our study; we would aim for three Dignity Therapy sessions, with the proviso that more than one actual Dignity Therapy session may be necessary. The people affected by dementia, who attended, welcomed the opportunity to discuss Dignity Therapy and asked if they could participate in a Dignity Therapy session.

The project team brought together clinicians from dementia, spiritual and palliative care to facilitate this feasibility work.

3. Aim & Objectives

The overall aim of this study was to assess the feasibility, acceptability and potential effectiveness of (modified) Dignity Therapy to improve the quality of life and reduce psychological and spiritual distress in older individuals with dementia.

The specific objectives were to determine:

1. Whether it is feasible to provide Dignity Therapy to older people newly diagnosed with dementia.
2. Whether Dignity Therapy is acceptable to older people newly diagnosed with dementia.
3. Whether Dignity Therapy has the potential to reduce dignity related distress and increase hopefulness and quality of life, as assessed by proposed outcome measures.
4. The willingness of participants to take part in the study.
5. The practicalities of using modified Dignity Therapy with people with dementia.
6. The time scale needed to collect data.

Research questions

How useful and feasible is Dignity Therapy for people with dementia?

Does Dignity Therapy have a role in enhancing quality of life for people with dementia?

4. Design and Methods

This study was a feasibility mixed method study.

The complex intervention (Dignity Therapy) (described above) was undertaken with patients diagnosed as having early stage dementia. Modification of Dignity Therapy was in relation to the content of the Dignity Therapy interview and the time needed for editing, since it was anticipated that the account might require greater editing skill than accounts produced by people without cognitive decline.

Patient and Public Involvement (PPI)

Patient and Public Involvement was a key feature of the success of this project. We involved people affected by dementia and key stakeholders (drawn from the Scottish Dementia Clinical Research Network) at all stages of the project.

The outcome measures were selected from; a scoping review of the literature, measures previously used in Dignity Therapy research, and in particular a discussion with the steering group and people affected by dementia (PPI group).

Data were collected via standard outcome measures (see below), before and after the intervention, and a qualitative interview 48 hours to one week following the completion of Dignity Therapy. Key stakeholders were invited to participate in a qualitative interview to ascertain their views, and a focus group was carried out with patients and family members. The Dignity Therapy documents created by the patients were also used to determine the type and scope of information provided, in order to inform the overall feasibility assessment. The key stakeholders were asked to share their views about the outcome measures which informed our choice of measures and how they were used.

All patients referred to the post diagnosis dementia service in one area in NHS Tayside (a community setting and service) who met the inclusion criteria were invited to participate in this feasibility study. The post diagnostic dementia service provides support for up to one year, for people with ESD. ESD involves moderate cognitive decline, with potential difficulty concentrating, and decreased memory of recent events (Reisberg et al 1982).

Inclusion and exclusion criteria are detailed in Table 1.

Table 1: Inclusion and exclusion criteria

Participants	Inclusion criteria	Exclusion criteria
Patients	<ul style="list-style-type: none"> • People with a diagnosis of ESD • Age 18 years or over • Able to provide written consent 	<ul style="list-style-type: none"> • No other psychiatric diagnosis or major behavioural issues • Patients who are unable to meet the inclusion criteria
Family Member	<ul style="list-style-type: none"> • Family member who is nominated by the patient • Age 18 years or over • Able to provide written consent 	<ul style="list-style-type: none"> • Family member who is unable to meet the inclusion criteria
Key Stakeholders	<ul style="list-style-type: none"> • Health professionals directly involved in caring for the person with dementia • Aged 18 years or over • Able to provide written consent 	<ul style="list-style-type: none"> • Health professionals who are unable to meet the inclusion criteria

Dignity Therapy outcome measures

It was considered important to consider outcome measures that would be relevant and appropriate, and to test their use in relation to feasibility and acceptability.

The outcome measures used were:

1. The Herth Hope Index (HHI)
2. The Patient Dignity Inventory (PDI)
3. Perceived Quality of Life, and Satisfaction with Quality Life Ratings

The Herth Hope Index (Herth 1992) was devised to evaluate emotional well-being, psychological well-being, and to give a brief psychosocial assessment measure. Specifically, it is implemented to assess levels of hope among those with acute, chronic and terminal illness (Herth 2000). It contains 12 short statements, each of which is scored on a 4 point range from strongly disagree to strongly agree. The statements are brief and use straightforward language, and responses only require a tick. It was therefore considered a suitable outcome measure in terms of content, appropriateness of assessment outcomes, and ease of completion. Accumulated scores range from 12 to 48, with higher scores indicating greater levels of hope. The tool has been implemented worldwide and has been assessed for reliability and face, content, and construct validity when used for adults with illness (Herth 1992, 2000).

The Patient Dignity Inventory (PDI) (Chochinov et al 2008) was devised during extensive work on dignity at end of life, and contains a 25 item questionnaire relating to activities and feelings about such issues as appearance, emotional state and relationships with others. Items in the questionnaire are rated on a 5 point scale ranging from 'not a problem' to 'an overwhelming problem'. Cumulative scores can range from 25-125, with higher scores indicating increasing problems. Permission for use in this research setting was granted by Professor Chochinov, who visited personally to meet with some of the research steering group (including people with early stage dementia) at the start of the project (August 2013). Questions on the PDI were developed to relate to key themes and subthemes of the Dignity Model (Chochinov et al 2008), which makes it a favourable tool to employ when measuring effects of Dignity Therapy. The use of the PDI is encouraged by Chochinov and colleagues, in

order to effectively measure a wide range of distress sources at the end of life. These include physical, psychosocial, existential and spiritual elements. Assessment of these can then stimulate actions by healthcare professionals to ameliorate such distress. The PDI was analysed for construct and content validity by Albers et al (2011) and was concluded to be an effective and appropriate measure for the study population (individuals with an advance directive in the Netherlands). This suggests that the PDI is relevant for populations besides those with cancer, such as those who participated in this current study. Although Albers et al (2011) found that comprehensiveness of items could potentially be enhanced, their analysis was based on the previous 22-item PDI, as opposed to the 25-item one used for this study.

Perceived Quality of Life, and Satisfaction with Quality of Life Ratings (Graham and Longman 1987) include two short questions, one relating to current quality of life, the other relating to satisfaction with quality of life (QoL). Scores are given on a scale of 1-10, with 1 being poor, and 10 being excellent. There is also a text box provided for open comments. This global QoL scale tool was developed and used in an investigation into quality of life and its association with symptom distress, social dependency and behaviour morale (Hall et al 2012a; Graham and Longman 1987; Young and Longman 1983). It allows participants themselves to assess their wellbeing, which is supported by Neugarten et al (1961) who suggests that individuals are best placed to make this judgement. Moreover, the tool itself is relatively simple in content, using the two questions that are rated on a clear scale. Yohannes et al (2011) analysed the reliability and validity of a similar, simple, single item measure QoL scale for adults with cystic fibrosis. They concluded that this was an effective tool for use in routine clinical practice.

Data analysis

Data (transcripts) from the Dignity Therapy documents, post Dignity Therapy interviews, focus group discussions, and stakeholder interviews were thematically analysed using a Framework Analysis approach (Ritchie et al 2013). This approach was developed specifically for applied or policy relevant qualitative research; the analytical process is explicit, and designed to be viewed and assessed by people other than the primary analyst, thereby

leaving a clear ‘audit trail’, facilitating rigor and consensus. The main aim of analysis was to assess the content relevance, and inform feasibility and acceptability assessments. Outcome measures were tabulated and assessed for indicators of understanding and ease/appropriateness of completion by the participants. Percentage changes were also calculated with a view to assessing the suitability and relevance of the outcome measures as potential data sources for future larger scale study.

5. Ethical Considerations

This study received approval from The East of Scotland Research Ethics Committee, (**13/ES/0130**) and NHS Tayside R&D (2013NS04).

No personal or identifiable information was used outwith the immediate research sites, where all data was held securely. During the transcription of interviews, participants were assigned a numerical value, and these have been used for any quotes.

6. Results and interpretation of findings

6.1 Participants

The total participant number was 27; this number included 7 people with early stage dementia (ESD), 7 family members, 7 stakeholder participants, and 6 focus group members (who were joined by 2 existing participants, making a total of 8 people in the focus group: 5 people with ESD, and 3 family members). Demographic information for participants is given in Tables 2 and 3 below.

Table 2: Participant demographics: people with ESD and family members

Participant number (person with ESD)	Age	Gender	Diagnosis; Date of diagnosis	Mini Mental State Examination (MMSE Score (out of 30))	Participating family member; age	Years known to person with ESD
1.	71	M	AD; Oct 2013	28	Wife; 72	49
2.	82	F	Mixed AD and Vascular Dementia; Sept 2013	27	Daughter; 44	44
3.	78	F	Mild AD and	27	Daughter; 54	54

			CVD; Sept 2013			
4.	81	M	AD; Dec 2013	26	Wife; 74	56
5.	79	M	Vascular Dementia; April 2010	Not recorded	Wife 68	50
6.	81	M	Vascular dementia; July 2013	21	Wife; 76	30
7.	77	M	AD; Aug 2007	30	Wife; 69	30

AD = Alzheimer's Disease; CVD = cerebrovascular disease MMSE: In general, scores of 27 or above (out of 30) are considered normal. However, getting a score below this does not always mean that a person has dementia <http://www.alzheimers.org.uk/>

Table 3: Participant demographics: Stakeholders

Participant ID	Gender	Professional role	Years in current post; Years qualified
SH 1.	F	Care manager	2; 10
SH 2.	F	Social care officer	9; 15
SH 3.	M	Chaplain	>1; 3.5
SH 4.	F	Consultant psychiatrist	22; 31
SH 5.	F	Senior charge nurse	27; 35
SH 6.	M	Consultant psychiatrist	26; 35
SH 7.	F	Chaplain	10 25

Data were collected between December 2013 and August 2014 in community locations in the east of Scotland. As noted in the methods section, results were obtained from five sources: The Dignity Therapy summaries, the post Dignity Therapy interviews, the focus group data, data from interviews with stakeholders, and data from outcome measures. Results from these sources are detailed below, with individual summaries of findings. The data set as a whole will be considered in the discussion section.

6.2 Dignity Therapy summary analysis

Main themes from this analysis are detailed below in Table 4, with sample quotes, followed by a summary.

Table 4: Dignity Therapy summary main themes

Main themes	Details	Sample quote
Life reflections	Looking back over the past, and taking the opportunity to select certain events that were of major significance to the individual.	'I've certainly enjoyed becoming a grandfather, and I think it's great to have time to get to know the grandchildren' (participant 4)
Providing explanations	Information about the past offered explanations relating to behaviours and habits that might be helpful for future care.	'I remember starting school - memories of the green paint, very calming. Green is still my favourite colour' (participant 2)
Personal legacy	Dignity Therapy offered the opportunity for participants to consider and document would like to say to their family members, as well as providing a historical legacy document.	'I would like to be remembered as a loving, helpful father. You get back what you give; you get less selfish as you get older' (participant 7)

Summary

Participants used Dignity Therapy as an opportunity to reflect on their life: their successes and regrets, as prompted by the Dignity Therapy question framework; they considered the things they valued and appreciated, including both people and achievements. Participants tended to be hopeful that they would be well thought of by their family and friends. Reflections were encouraged to be retrospective rather than forward thinking, and participants displayed a good ability to recollect minute details from the past. During their accounts participants divulged information about likes, dislikes and the origins of habit that might be helpful in explaining future reactions and behaviours. Such information might not have been divulged through other means. Arguments and difficulties were brought to the fore for some participants, but there was a desire to put these into perspective, as they considered their life as a whole.

With regard to gender differences, work and hobbies tended to feature more prominently in the male participants' recollections and be seen as a greater part of their identity than in the female accounts, which tended to discuss relationships and family to a greater extent. The accounts from participants tended to be very open about emotions, reactions and family situations. This may have been an indication that the participants trusted and felt comfortable sharing these views with the Dignity Therapists, who were also experienced health practitioners and interviewers; such disclosures may have also indicated a degree of disinhibition, sometimes seen as a feature of dementia (Starkstein et al 2004). While it may be difficult to judge whether this is the case, it is a consideration to be borne in mind in research involving people with dementia, especially in terms of sensitive reporting of the personal information that may be divulged.

Generally participants described working very hard, even when quite young. This was seen as the norm for many of the participants. Leaving school at an early age was not necessarily seen as a barrier to progressing in employment, and there were opportunities for advancement, if not the acquirement of formal qualifications, for these participants. This may indicate generational differences in values and attitudes worthy of discussing further in future studies, especially relating to the understandings and beliefs held by the current workforce that may shape their attitudes to older people (Futureversity 2012; Dept of Work and Pensions 2013).

At this stage in their condition there were no problems identified from the accounts that indicated that participants had difficulty fulfilling the main information requirements necessary to complete a Dignity Therapy document that had relevance and meaning to them as individuals, as evidenced by their responses when hearing the document being read back. Participants appeared to gain fulfilment from taking part; they also expressed an appreciation of the fact that people were taking an interest in them and their condition. This may not be surprising, given the consideration that the voices of people with dementia may go unheard (Williamson 2012).

6.2 Post Dignity Therapy interview analysis

Feedback regarding the **Dignity Therapy** process was obtained from the post interview interviews, and main themes are identified in Table 5 below.

Table 5: Main themes from post Dignity Therapy interview

Main themes	Details	Sample quote
A life in context	The Dignity Therapy process and document helped to place the person’s life in relation to their past, and in relation to their family. It provided history and legacy. It provided the opportunity to reflect on positive and negative life experiences.	‘When you hear someone else saying it, it hits you in the back of the throat a wee bit. But it’s all part of the story’ (participant 1).
A key to connect	The Dignity Therapy document offered information that could help with future connections, by encouraging dialogue about familiar and remembered events from the past. It could help to develop commonality of interest between people who became involved with the person after they were no longer able to tell or remember their own story spontaneously	‘It (Dignity Therapy document) will act as an aide memoire. It might help strangers to help him, give background’ (wife of participant 4).
The unknown and unspoken future	Although there was some avoidance of thinking about or discussing the future and what lay ahead too deeply, the Dignity Therapy document provided a sensitive way of allowing legacy and history to be preserved, without causing unnecessary distress or unwanted discussions about the future, for either patients or their family members.	‘It’s memory stimulation – it’s the only way to face it at the moment, unless they come up with a drug to bring your memory back’ (participant 7).

Summary

All participants found the experience of taking part beneficial, and generally felt the Dignity Therapy document was accurate. Some wished to make minor adjustments to the wording and flow of the story. There was some concern that people might misunderstand what had been written, but family members were supportive and did not feel the minor inaccuracies were that important; they were part of the story, told at that time. Family members also had a good understanding of the personal nature of the story telling, and did not feel the need to correct or interrupt to any great extent if they were present at the time. They

expressed an interest in the earlier parts of participants' lives, that they were not previously aware of.

Participants found Dignity Therapy helped with self-reflection, and hearing their story back was sometimes quite an emotional experience. This in itself can be a thought of as beneficial, as nondisclosure of emotions has been shown to inhibit a person's adjustment to illness (Cuevas and Clark 2008). Encouraging reflection can be a useful aid to coping, not only for people with dementia, but also their family (Davis 2009) and nursing staff (Jones 2008).

Generally, participants felt the Dignity Therapy document would be of benefit for future years, when it might help family or carers to connect better with the person, and act as a reminder, which would help preserve dignity. With further regard to diagnosis and the future, this was something participants were coming to terms with, but indicated they did not wish to think too deeply about at this present time.

It was suggested that photos might be a useful addition, and subheadings were suggested as a way of structuring the story further. The Dignity Therapy document was felt to be more detailed and more about history and emotions than other similar documents. It helped participants to record things that they might find difficult to say in person. Access rights to document were highlighted, but generally participants and family members felt it could be widely helpful.

6.3 Focus group analysis

The focus group meeting was held in July 2014 with two researchers facilitating (BJ and CMcC). Main themes from these discussions are noted in Table 6, below.

Table 6: Focus group themes

Main themes	Details
Dignity Therapy as	Disclosure of personal information and knowledge; importance of interest

an opportunity	being taken in the person with ESD
Dignity Therapy delivery	Importance of environment, timing, those present, and nature/skill/role of the Dignity Therapist
Dignity Therapy in practice	Consideration of type and content of disclosure, anticipated audience and context; nature of Dignity Therapy outcome measures; naming, explaining and 'packaging' of Dignity Therapy

Summary of focus group discussions

Initial concerns were raised by participants about their diagnosis, means of receiving that diagnosis, and the uncertain definition of 'early stage' dementia. Even although the research was not related to these areas, they were still raised as significant concerns for the participants. This was noted as an adjunct issue: **Diagnosis and Implications**.

Following an overview of the study aims and purpose by one of the researchers, comments were made by participants about the interesting and enjoyable nature of creating the document; the opportunity to learn things not previously known about the person with ESD, even by close family. Comments were also made about the outcome questionnaires, with one mention of the 'woolly' nature of the questions, and the need for the time between meetings to be fairly short to help with memory. The fact that the Dignity Therapy could be done at home, in familiar surroundings, was mentioned as beneficial. The caring, empathic approach of the Dignity Therapist was emphasised, as well as the flexible nature of their working practice to facilitate their involvement in the process.

People who had not taken part in Dignity Therapy, but were still part of the focus group, felt it would be a beneficial thing to do. The interest taken in the individual with ESD was considered important, and the opportunity for a family member/friend to be present, if desired, was also mentioned, as was their role on acting as a prompt. The opportunity to correct any mistakes was highlighted, and the personal nature of disclosures that were suitable for the audience that would be reading them was also considered. The practicalities of who to give the document to (paper or e-copy), and the individual choice about who that

might be (family/professionals) were discussed. The use of photographs in addition to the Dignity Therapy document was considered as an individual thing.

The title of ‘Dignity Therapy’ was discussed, with mixed views about whether it was a good phrase to use; the difference between that and Life History work was also mentioned. Issues surrounding the disclosure of diagnosis and the consequences (e.g. relating to ability to drive) were highlighted again by participants at the end of the formal focus group discussion.

6.4 Stakeholder interview analysis

Findings from interviews with the seven stakeholders indicated that they felt Dignity Therapy could be used in early dementia, and that this could make a positive difference to future care; they tended to feel that the story was best told by the person with ESD, without input from the family member, at least initially. They felt the Dignity Therapy was more individual than other approaches currently in use. When asked for suggestions about the type of person who might deliver Dignity Therapy, they felt this could be carried out by people in a number of different roles, but training and sensitivity would be required. Main themes derived from the stakeholders are detailed in Table 7 below.

Table 7: Stakeholder interview themes

Main themes	Details
Preserving self	Dignity Therapy allows person and their story to be told and remembered, therefore preserving something of themselves when they are no longer ‘present’
Details make a difference	The small details, often forgotten by others, even close family, can allow care to be more individualised in the future, especially when the person is no longer able to express themselves well
People versus systems	Dignity Therapy allows person-centeredness to be maintained, without which systemised care might dominate

6.5 Outcome measures

With regard to the outcome measures (HHI, PDI, and Quality of Life ratings) four participants completed all measures before and after Dignity Therapy. One participant completed all three measures before Dignity Therapy, and two completed all three measures after Dignity Therapy.

There did not appear to be any major participant difficulties with completing the outcome measures. In the focus group interviews, one participant did indicate that some of the questions seemed slightly vague ('woolly'), but on the whole, there were no adverse responses, indicating acceptability. Herth Hope Index results are detailed in Table 8 below, with additional comments relating to completion.

Table 8: Herth Hope Index results

Participant	HHI Pre Dignity Therapy	HHI Post Dignity Therapy	Percentage change	Comments
1	45	36	-18.7%	Minor inconsistencies in completion and some evidence of misunderstanding of rating system
2	36	39	+ 6.25%	Consistent completion of rating, indicating understanding
3	37	38	+2.08%	Consistent completion of rating, indicating understanding
4	36	36	0	Consistent completion of rating, indicating understanding; although overall score did not change, individual item scores were different between pre and post, indicating independent thought/judgement ability
5	38	Not completed	n/a	Appropriate completion, indicating understanding
6	Not completed	34	n/a	Appropriate completion, indicating understanding
7	Not completed	37	n/a	Appropriate completion, indicating understanding

As can be seen from Table 8, only one participant appeared to have minor difficulty with understanding and completion of this measure. Given the intended use for people with early stage dementia (ESD), it would seem appropriate to ensure some guidance is available to support completion, if necessary.

Quality of Life Scores are noted in Table 9 below, with scores for perceived QoL and satisfaction with QoL being collated together since the assessment of interest for this feasibility study related to acceptability and completion ability, rather than the production of a result analysis.

Table 9: Quality of Life results

Participant	QoL Pre Dignity Therapy	QoL Post Dignity Therapy	Percentage change	Comments
1	18	20	+10%	Consistent completion of rating, indicating understanding; participant commented on change in QoL in free text box, again indicating understanding of measure
2	16	17	+5%	Consistent completion of rating, indicating understanding; participant commented on health in free text box, again indicating understanding of measure
3	17	15	-10%	Consistent completion of rating, indicating understanding. QoL had dropped during 4 month gap between scores, which might be consistent with family worries, as reported in Dignity Therapy.
4	16	17	+5%	Consistent completion of rating, indicating understanding; participant commented on age in free text box, again indicating understanding of measure
5	18	Not completed	n/a	Appropriate completion, indicating understanding
6	Not completed	17	n/a	Appropriate completion, indicating understanding
7	Not completed	18	n/a	Minor inconsistency with completion, but comment in free text box indicated understanding

Generally, there appeared to be a good understanding of this measure, and comments made by participants indicated they were thinking and considering appropriately. Results indicate that analysis and assessment of scores can be usefully informed by other data in the study.

The Patient Dignity Inventory was the longest of the outcome measures used, and summated scores are indicated in Table 10 below.

Table 10: PDI results

Participant	PDI Pre Dignity Therapy	PDI Post Dignity Therapy	Percentage change	Comments
1	28	30	+1.6%	Consistent completion of rating, indicating understanding
2	34	32	-1.6%	Consistent completion of rating, indicating understanding
3	30	33	+2.4%	Consistent completion of rating, indicating understanding.
4	35	34	-0.8%	Consistent completion of rating, indicating understanding
5	42	Not completed	n/a	Appropriate completion, indicating understanding
6	Not completed	38	n/a	Appropriate completion, indicating understanding
7	Not completed	30	n/a	Appropriate completion, indicating understanding

As can be seen from Table 10, there were no apparent difficulties with completing the PDI. As stated above, potential scores can range from 25 (few or no problems) to 125 (significant problems). Scores from these participants indicate that, at this stage in their diagnosis, perceived problems relating to issues that might affect dignity were generally low, and did

not change to a great extent in the 3-5 month gap between measurements. Negative scores indicate a reduction in worry (and vice versa) following Dignity Therapy, and as such these scores have the potential to contribute to an impact evaluation of Dignity Therapy in future studies. Although the length of this questionnaire might preclude its use in later stage dementia, it would certainly seem a useful indicator of perceived dignity in the early to mid-stages.

Summary

The outcome measures used for this feasibility study appear to be appropriate and acceptable to participants, with the proviso that assistance with understanding and completion is available, if required. Although, the ability of the person with ESD to assess concepts such as hope and issues affecting dignity may lessen during the progression of their condition, at this stage, and for the purposes of the study, such measures can give useful indicators about the psychological state of the participant, and whether taking part in the Dignity Therapy intervention has had an impact on this. Relating this to other data acquired from the Dignity Therapy document, and post Dignity Therapy interview, may yield interesting insights into the impact of Dignity Therapy on the individual, and provide outcome indicators of change. Although, not appropriate for the purposes of a feasibility study, analysis of such results with a larger cohort of participants may also yield interesting trends and inferences across participants.

7. Discussion

The incidence and prevalence of dementia has been highlighted as an increasing future challenge (Alzheimer Scotland 2013), with preserving dignity being considered a major factor (Scottish Government 2013). Given that many people with ESD will continue to live in the community as their condition progresses, with the support from relatives, friends, and community staff (Scottish Government 2013), it is important that interventions that may assist and shape future care are facilitated during a time when input from people with ESD is possible. This is especially true if avoidable admissions to hospital are to be prevented (Alzheimer's Society 2013).

The aim of this study was to assess the feasibility, acceptability and practicality of using Dignity Therapy as a means to help future care and understanding of the person with ESD, and support their individuality, thereby assisting the preservation of dignity. Such support may impact on their likelihood of being able to remain being cared for in the community; greater understanding and support from family and healthcare staff can lead to less distress for both carers and people with dementia, and it has been shown that care staff actively want to provide such support (Goddard et al 2013b). However, as Goddard et al (2013b) conclude, expertise regarding care, particularly towards end of life, may be lacking, which may impact on the provision of dignified care (Thompson et al 2011).

People with dementia are often excluded from research (Hubbard et al 2003) due to the challenges involved, and perceptions of their ability to participate. As a result there is a limited pool of research evidence available. This study sought to test the feasibility of an intervention to improve future care for people with ESD, as well as their ability and willingness to engage in such research. The study has given good indicators of capability and desire to take part. It has shown that the Dignity Therapy process was well received by people with ESD, their family members, and the stakeholders whose views were sought as part of the study. All participants felt that information in the Dignity Therapy summary could help family and carers of the person with ESD as their condition progresses. Methods of data collection (i.e. post Dignity Therapy interviews and outcome measures) did not pose any significant difficulties for participants, and they also yielded results that could prove informative if used in a future larger scale study. Dignity Therapy therefore has the potential to assist the person with dementia to remain 'centre stage' in their own life story narrative (Angus and Bowen-Osborne 2014: 147).

It was considered essential to conduct a feasibility study as a precursor to further study; feasibility evaluation is a vital part of developing complex interventions, allowing the practical elements and acceptability of an intervention to be tested and, if necessary, altered, prior to pilot and main study evaluation (Medical Research Council 2008). This was particularly important due the problems people might have with ESD, such as memory and communication problems, or confusion (Alzheimer's Society 2011).

With regard to the modification of Dignity Therapy for this group of participants, the content of the Dignity Therapy interview followed the original interview guide. We agree with the finding of Hall's study (Hall et al 2012b) that the Dignity Therapy document took longer to edit than in other settings (e.g. palliative care). However, since participants with Early Stage Dementia are not at 'the end of life', this did not prove to be problematic. Nevertheless, this additional time would need to be factored into further research or use in clinical care. The second meeting with the participant, when the Dignity Therapy document was read through, did provide a further opportunity to discuss issues, with additional information then being added to the final document.

Feedback from practitioners working with participants following their inclusion in the study indicated that participants were 'more positive regarding openly exploring their inner thoughts and feelings surrounding their life events'. Participants also reported feeling relieved about having this as a legacy to pass to their family. This feedback was viewed as further endorsement of the value of Dignity Therapy to the participants.

This study has given good indicators that the method and outcome measures proposed were appropriate and acceptable to this group of participants, and would transfer well to a larger scale study. In addition to these considerations, a feasibility study can allow resource projections (time, personnel, expertise, finance) to be made that may support greater likelihood of successful future research stages. This is particularly relevant for complex interventions, and in situations where there is limited information about potential challenges. With regard to resource considerations, in addition to the extra time required to conduct Dignity Therapy with participants with dementia, the cost of training dignity therapists would also have to be assessed. At present, Dignity Therapy training is only available through a specialist training programme in Canada. For more wide-spread use of the intervention, consideration would have to be given to, for example, a train the trainer approach with the two trained Dignity Therapists in Scotland (who are also qualified educators) providing local training, support and supervision.

Limitations

This was a small feasibility study conducted in one part of the UK. As such, the findings are limited by scope and size. The study did not have the aim of producing an assessment of effectiveness, although useful indicators have been given about the appropriateness of outcome measures for future study.

8. Conclusion

This study has shown that Dignity Therapy is feasible, acceptable and potentially effective for older individuals with dementia; the outcome measures have the potential to indicate changes in quality of life and psychological and spiritual distress as a result of Dignity Therapy, and are therefore relevant for use in further larger scale study that will evaluate effectiveness. Dignity Therapy can provide detail to inform care and nursing practice for the person with dementia. The provision of care that is informed by Dignity Therapy has the potential to be more person-centred, and could therefore enhance dignity for people with dementia.

“So after witnessing her mind smoulder with disease and living through the slow burn, I want to shout that there was more, and that I can remember when things were different. I want it to be known that there were days when the sun shone on my grandmother and she was strong and brave, confident in her step and sure in her voice, and that the world was too small to hold her love. I want that to be said out loud and for the remnants of her life not to be allowed to waft away without an acknowledgement of who she was and what she did”
(Davis 2009).

9. Recommendations

This feasibility study has indicated that Dignity Therapy has the potential to inform and enhance the care of people living with dementia in the community. Further study with more in-depth analysis of findings is necessary to provide a more detailed evidence base to guide practice and inform policy. We recommend that this feasibility study forms the basis for further study, advocating the prospective benefits to patients with dementia, family members, and community nursing practice.

10. Impacts of the Project

- a. This study has provided the opportunity to examine the feasibility of using the Dignity Therapy intervention for people with early stage dementia. As such, it has provided evidence that the intervention is acceptable, and has the potential to improve quality of life, care, and dignity.
- b. *Describe the impact on the development of individuals and the team, in particular around leadership and research capability.*

This study gave the opportunity for a feasibility analysis and evaluation to take place, with the differing skills and emphasis that this requires. It therefore added to research team members' understanding of the different evaluation methods that are required for this stage in the research process. In addition, the project allowed a nurse, who did not have experience of previously working in academic research, to be seconded, and to therefore develop skills and knowledge in participating in academic research which will ultimately benefit practice. The multi-professional project team also enhanced the study development and findings.

11. Dissemination Plan

- a) We will publish 2 papers in peer reviewed journals
- b) We have presented results at 2 international conferences: International Palliative Care Conference, Montreal Sep 2014 and Alzheimer's Europe Conference, Glasgow Oct 2014. We will also present at European Association of Palliative Care, Denmark 2015.
- c) We will present the results locally in NHS Tayside and to QNIS

12. Future developments/ next steps

This project has given good indicators that Dignity Therapy is feasible and potentially beneficial for people with early stage dementia. The knowledge and insights gained will form the basis of further research proposals and funding applications. Consideration will also be given to the inclusion of people with more developed disease progression.

13. References

- Albers G, Pasma HRW, Rurup ML, de Vet HCW, Onwuteaka-Philipsen BD (2011) Analysis of the construct of dignity and content validity of the patient dignity inventory. *Health and Quality of Life Outcomes*. 9: 45
- Alzheimer's Society (2011) *The progression of Alzheimer's disease and other dementias*. Alzheimer's Society, London
- Alzheimer's Society (2012) *My life until the end: Dying Well with Dementia*. Alzheimer's Society, London
- Alzheimer's Society (2013) *Formal care of people with dementia*. Alzheimer's Society, London
- Alzheimer's Society (2014) *A good life with dementia*. Alzheimer's Society, London
- Alzheimer Scotland (2013) 'Getting to Know me'. Alzheimer Scotland, Edinburgh
- Alzheimer's Research UK 2013 *Defeat Dementia: The Evidence and a Vision for Action*. Alzheimer's Research UK, Cambridge
- Angus J, Bowen-Osborne S (2014) A self narrative of life-long disability: A reflection on resilience and living with dementia. *Dementia* 13: 147-159
- Bentley B, O'Connor M, Breen L, Kane R (2014) Feasibility, acceptability and potential effectiveness of Dignity Therapy for family carers of people with motor neurone disease. *BMC Palliative Care* 13: 12
- Bleathman C, Morton I (1996) Validation therapy: a review of its contribution to dementia care. *British Journal of Nursing* 5: 866 – 868
- Brooker D (2004) What is person centred care for people with dementia? *Reviews in Clinical Gerontology* 13: 215-222
- Brooker D, La Fontaine J, De Vries K, Porter T, Association for Dementia Studies, Surr C, Bradford Dementia Group (2011) *How can I tell you what's going on here? PANICOA*, University of Worcester. www.panicoa.org.uk
- Chang H, Pang S (2010) Let me talk – an advance care planning programme for frail nursing home residents. *Journal of Clinical Nursing* 19: 3073 – 3084

Chochinov H, Hassard T, Kristjanson L, McClement S, Harlos M (2005) Dignity Therapy: a novel psychotherapeutic intervention for patients near the end of life. *Journal of Clinical Oncology* 23: 5520 – 5525

Chochinov HM, Hassard T, McClement S, Hack T, Kristjanson LJ, Harlos M, Sinclair S, Murray A (2008) The patient dignity inventory: a novel way of measuring dignity related distress in palliative care. *Journal of Pain and Symptom Management* 36: 559-71

Chochinov H, Kristjanson L, Breitbart W, McClement S, Hack T, Hassard T, Harlos M (2011) The effect of Dignity Therapy on distress and end-of-life experience in terminally ill patients: a randomised controlled trial. *The Lancet* DOI 10.1016/S1470 – 2045(11)70153-X

Chochinov H, Cann B, Cullihall K, Kristjanson L, Harlos M, McClement S, Hack T, Hassard T (2012) Dignity Therapy: a feasibility study of elders in long term care. *Palliative and Supportive Care* 10: 3-15

Cuevas H, Clark AP (2008) Using reflection as a nursing intervention. *Clinical Nurse Specialist* 22: 122-123

Davis J (2009) *Dementia: a personal reflection*. Ursuline Senior Services, Pittsburgh, PA

Department of Health (2009) *Living Well with Dementia: A National Dementia Strategy*. Dept of Health, Leeds.

Department of Health (2012) *Prime Minister’s Challenge on Dementia –Delivering Major Improvements in Dementia Care and Research by 2015*. Department of Health, London

Department of Health (2013) *G8 Dementia summit*.
<http://dementiachallenge.dh.gov.uk/2013/12/12/g8-dementia-summit-agreements/>

Department of Work and Pensions (2013) *Improving Health and Work: Changing Lives*. UK Government, London

De Vries K (2013) Communicating with older people with dementia. *Nursing Older People* 25: 30 -37

Dröes A, Boelens-Van der Knoop E, Bos J (2006) Quality of life in dementia in perspective: an explorative study of variations in opinions among people with dementia and their professional caregivers and in the literature. *Dementia* 5: 533 DOI 10.1177/1471301206069929

Futureversity (2012) *Closed Doors: Youth and Jobs Survey*. Futureversity, London

Goddard C, Speck P, Martin P, Hall S (2013a) Dignity Therapy for older people in care homes: a qualitative study of the views of residents and recipients of 'generativity' documents. *Journal of Advanced Nursing* 69: 122-32

Goddard C, Stewart F, Thompson G, Hall S. (2013b) Providing end-of-life care in care homes for older people: a qualitative study of the views of care home staff and community nurses. *Journal of Applied Gerontology* 32: 76-95

Graham KY, Longman AJ (1987) Quality of life and persons with melanoma. Preliminary model testing. *Cancer Nursing* 10: 338-46

Hall S, Goddard C, Speck P and Higginson I (2012a) 'It makes me feel that I'm still relevant': a qualitative study of the views of nursing home residents on Dignity Therapy and taking part in a phase II randomised controlled trial of a palliative care psychotherapy. *Palliative Medicine* 27: 358 – 66

Hall S, Goddard C, Opio D, Speck P, Higginson IJ (2012b) Feasibility, acceptability and potential effectiveness of Dignity Therapy for older people in care homes: a phase II randomized controlled trial of a brief palliative care psychotherapy. *Palliative Medicine* 26: 703-712

Herth K (1992) Abbreviated instrument to measure hope: development and psychometric evaluation. *Journal of Advanced Nursing* 17: 1251-1259

Herth K (2000) Enhancing hope in people with a first recurrence of cancer. *Journal of Advanced Nursing* 32: 1431-1441

Hubbard G, Downs MG, Tester S (2003) Including older people with dementia in research: challenges and strategies. *Aging & Mental Health* 7: 351-362

Jones E 2008 Reflective practice in dementia care. *Journal of Dementia Care* 16: 19-20

Law E, Russ T, Connelly P (2013) What motivates patients and carers to participate in dementia studies? *Nursing Older People* 25: 31-36

Manthorpe J, Illiffe S, Samsi K, Cole L, Goodman C, Drennan V, Warner J (2010) Dementia, dignity and quality of life: nursing practice and its dilemmas. *International Journal of Older People Nursing* 5: 235-244

McClement S, Chochinov H, Hack T, Hassard T, Kristjanson L, Harlos M (2007) Dignity Therapy: family member perspectives. *Journal of Palliative Medicine* 10: 1076 – 82

Medical Research Council (MRC) (2008) *Developing and Evaluating Complex Interventions: New Guidance*. MRC, London

Montross L, Meier E, de Cervantes-Monteith K, Vashistha V, Irwin S (2013) Hospice staff perspectives on Dignity Therapy. *Journal of Palliative Medicine* 16: 1118-20

Neugarten B, Havighurst R, Tobin S (1961) The measurement of life satisfaction. *Journal of Gerontology* 16: 134-143

Reisberg B, Ferris SH, de Leon MJ, Crook T (1982) The global deterioration scale for assessment of primary degenerative dementia. *American Journal of Psychiatry* 139: 1136-1139

Ritchie J, Lewis J, Nicholls CM, Ormston R (Eds) (2013) *Qualitative Research Practice: A Guide for Social Science Students and Researchers*. Sage, London

Ryan T, Ingleton C, Gardiner C, Nolan M, Gott M (2009) Supporting people who have dementia to die with dignity. *Nursing Older People* 21: 18 – 24

Sabat (2001) *The Experience of Alzheimer's Disease: Life Through a Tangled Veil*. Blackwell, Oxford

Sampson E, Jones S, Thunè-Boyle L, Kukkastenvemas R, King M, Leurent B, Tookman A, Blanchard M (2010) Palliative assessment and advance care planning in severe dementia: an exploratory randomised controlled trial of a complex intervention. *Palliative Medicine* 25: 197 -209

Scott H (2013) Talking about death in dementia. *End of Life Journal* 3: 1-4

Scottish Government (2012) *Scotland's National Dementia Strategy: 2 years on*. Scottish Government, Edinburgh

Scottish Government (2013) *Scotland's National Dementia Strategy 2013-2016*. Scottish Government, Edinburgh

Simpson D, James I, Ballard C (2004) Non pharmacological interventions in dementia. *Advances in Psychiatric Treatment* 10: 171 – 177

Starkstein S, Garau ML, Cao A (2004) Prevalence and clinical correlates of disinhibition in dementia. *Cognitive & Behavioural Neurology* 17: 139-147

Thompson GN, McClement SE, Chochinov HM. (2011) How respect and kindness are experienced at the end of life by nursing home residents. *Canadian Journal of Nursing Research* 43: 96-118

Van der Steen J, Radbruch L, Hertogh C, de Boer M, Hughes J, Larkin P, Francke A, Jünger S, Gove D, Firth P, Koopmans R, Volicier L (2013) *White Paper defining optimal palliative care*

in older people with dementia: a Delphi study and recommendations from the European Association for Palliative Care. Palliative Medicine DOI: 10.1177/0269216313493685

Williamson T (2012) A Stronger Collective Voice for People with Dementia. Joseph Rowntree Foundation, York

Yohannes AM, Dodd M, Morris J, Webb K (2011) Reliability and validity of a single item measure of quality of life scale for adult patients with cystic fibrosis. Quality of Life Outcomes 9: 105

Young KJ, Longman AJ (1983) Quality of life and persons with melanoma: a pilot study. Cancer Nursing 10:338-346