



Institute of  
**Health and Wellbeing**

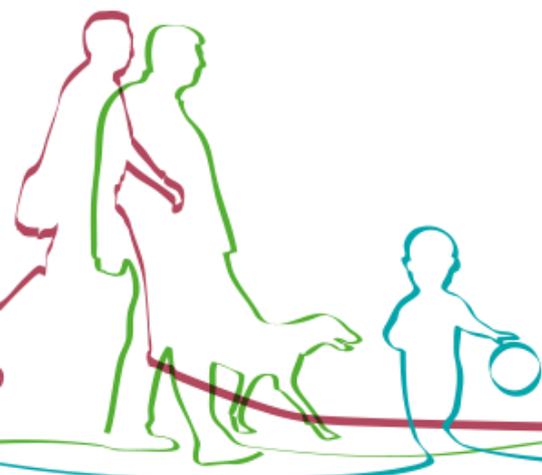
Sharing Stories for Wellbeing: An  
Evaluation

Jane Youell, Alison Ward

2015

Institute of Health & Wellbeing  
The University of Northampton  
Boughton Green Road  
Northampton  
NN2 7AL

(01604) 892887



# Institute of Health and Wellbeing

The Institute of Health and Wellbeing (formerly the Centre for Health and Wellbeing Research) is an inter-disciplinary and inter professional centre of excellence in Health and Wellbeing working with health and social care providers, commissioners and other partners to support research, enterprise and innovation relevant to the health and wellbeing of the population.

The Institute is fully resourced to undertake evidence review and primary data collection using both quantitative and qualitative evaluation methods (e.g. large questionnaire surveys, social surveys, one-to-one interviews, SPSS analysis, focus groups, in-depth discussion groups, semi-structured and open interviews, and tape transcriptions). All members of project teams have extensive experience of research and evaluation projects.

During 2009-14 members of this project team have successfully contributed to the following research and evaluation projects:

- Singing for the Brain Pilot Project Evaluation (project commissioned by Alzheimer's Society Northamptonshire).
- Personal Health Budgets for Carers in Northamptonshire: An Evaluation (project commissioned by NHS Northamptonshire).
- An evaluation of the Pilot Healthchecks scheme in Northamptonshire (project commissioned by NHS Northamptonshire).
- An evaluation of the General Practitioner Referral Tool, Pathfinder (project commissioned by Nene Commissioning).
- An evaluation of the Zoned Asthma Action Plan card (project commissioned by Nene Commissioning).
- A Community Cardiovascular Unit Consultation (project commissioned by Bedfordshire Clinical Commissioning Group).

For more information on our current projects, please visit

[www.northampton.ac.uk/institute-of-health-and-wellbeing](http://www.northampton.ac.uk/institute-of-health-and-wellbeing)

# Contents

<b>Institute of Health and Wellbeing .....</b>	<b>i</b>
<b>Contents.....</b>	<b>ii</b>
<b>1 Introduction.....</b>	<b>1</b>
<b>2 Aims.....</b>	<b>3</b>
<b>3 Methods .....</b>	<b>4</b>
<b>3.1 Patient Paper Questionnaire .....</b>	<b>4</b>
<b>3.2 Face to face Interviews with Participants .....</b>	<b>5</b>
<b>3.3 Staff and Family Face to Face Interviews.....</b>	<b>5</b>
<b>3.4 Participant Observation .....</b>	<b>5</b>
<b>3.5 Analysis .....</b>	<b>6</b>
<b>4 Research Findings .....</b>	<b>7</b>
<b>4.1 Pre and Post Questionnaire.....</b>	<b>7</b>
<b>Table 1: Demographic Profile .....</b>	<b>7</b>
<b>4.2 Observations.....</b>	<b>7</b>
<b>4.3 Interviews .....</b>	<b>9</b>
4.3.1 Pleasure .....	9
4.3.2 What makes you you.....	12
4.3.3 More than just a patient.....	15
4.3.4 Benefits beyond the group .....	17
<b>5 Conclusion and Recommendations .....</b>	<b>20</b>
<b>5.1 Recommendations .....</b>	<b>21</b>
<b>References .....</b>	<b>23</b>

# 1 Introduction

Storytelling and story sharing have been an enduring part of human culture from cave paintings, the myths of ancient Gods, the oral traditions of sitting around the camp fire to current day cinema and social media. Part of human nature is to share our stories so that we learn from each other and provide an opportunity for reflection, to make sense of our experiences (Abma, 2003; Holm *et al.*, 2005; Ransome, 2012) and the world around us (Romanoff & Thompson, 2006). Konner (2010) contends that without sharing our narratives and histories these simply remain private and do not then add to the 'collective', while Frank (2010) argues that stories act as more than just entrainment or 'curiosity' but imbue a sense of self, are part of the development of relationships, provide purpose and affect 'what people are able to see as real, as possible...' (p.iii). This notion is expanded by Romanoff & Thompson (2006), who wrote that through stories we 'give meaning to our past and give direction to our future' (p,309). Abma (2003), working with storytelling workshops for health professionals in palliative care in the Netherlands, saw this as an opportunity for people to 'communicate experiences, relate stories to each other and collaboratively create meaning' (p.223). Additionally, it was a way in which to enable collaborative learning.

The process of engaging in a storytelling workshop enables a dual process of both telling your own story and of listening to other people's, of having a shared dialogue, and as Abma (2003) states, this provides a 'search for knowledge, [and] understanding' (p.223). The importance of using storytelling approaches in palliative care is in this shared knowledge and understanding, as people come to terms with a diagnosis which affects every aspect of their lives. There is a need for a re-evaluation of a person's own narrative and reflection upon their lives as a way to find meaning (Romanoff & Thompson, 2006). The therapeutic value on the individual has been reported through improved wellbeing, dignity, quality of life, reduced depression, improved/preserved self-identity and a way of connecting with others (Romanoff & Thompson, 2006; Heggstad and Slettebø, 2015; Heiney *et al.*, 2015; Synnes, 2015). The role of storytelling is not only for the benefit of the person with the terminal illness but can also support wider family members, enabling them to find meaning in the changes to their family structure (Nadeau, 1998; Nadeau, 2001), enabling families to heal and for memories to endure beyond the death of a family member (Romanoff & Thompson, 2006). De Jong and Clarke (2009) write that the benefits of storytelling in palliative care provides meaning and can 'heal' both the person telling the story and the person listening, with the listener being an active and vital part of the storytelling process.

Local storyteller and biographer Miranda Quinney has been volunteering her services at Peace Hospice Care in Watford since 2011, and has been encouraging patients to share their life stories at a series of facilitated workshops. In 2013, Miranda was joined by Doreen Pattenson, senior social worker at Peace Hospice Care. On observing the workshops, it was identified anecdotally that, in addition to the practical benefits of saving family stories, patients participating in the programme visibly brightened and reported enhanced feelings of wellbeing, happiness and a generally improved quality of life. The technique used was formerly known as Life Stories, but now operates under the name Sharing Stories for Wellbeing. Sharing Stories for Wellbeing will be launching a nationwide train the trainer Story Maker programme for hospices interested in training their own volunteer Story Makers (i.e. workshop facilitators) in November 2015. Their technique is one which allows people to share their life stories in a group workshop. These stories are then captured by a facilitator to be reproduced in written form and provided or 'gifted' to the participant to keep and share. The sessions enable people to meet and share stories about their lives. The central objectives of Sharing Stories for Wellbeing are a) to recount and record own life stories; b) provide opportunities to reflect, accept and understand; c) provide opportunities to acknowledge the value of life and the contribution made; d) provide opportunities to make sense of experiences, express emotions and be able to move on. The sessions were promoted as 'an opportunity to capture and record your own life stories – anecdotes, words of wisdom, reminiscences and experiences'. As with previous research, informal patient feedback from Sharing Stories for Wellbeing sessions has found improved self-esteem, the feeling of being valued, the positive impact of being listened to at a time of great personal distress. In addition, patients have referred to the story sharing and recording process as one which has helped them to resume control over their lives and rebuild their self-confidence, and self-esteem. This process creates attitudes towards the self which are favourable and develop positive feelings of self-worth.

Peace Hospice Care (Watford) and the Hospice of St Francis (Berkhamsted) are working in partnership to deliver innovative day services for patients, carers and their wider communities across South and West Hertfordshire. A range of services aiming to improve health, wellbeing, independence and confidence are delivered on both sites in the Starlight and Spring Centres.

This evaluation was therefore timely in providing further insight into the role of Sharing Stories for Wellbeing workshops sessions for people in palliative care and understanding its impact on the participants, staff and family members. The evaluation was based on a five weekly programme run at Peace Hospice Care in May-June 2015.

## 2 Aims

The overall aim of the evaluation was to understand the impact of involvement in the Sharing Stories for Wellbeing workshops for participants, family members and staff.

The objectives for this evaluation were:

- To understand the impact on wellbeing and potential benefits for participants of the Sharing Stories for Wellbeing workshops.
- To understand the benefits of the Sharing Stories for Wellbeing workshops on family members of participants.
- To understand the benefits of the Sharing Stories for Wellbeing workshops on hospice staff.
- To provide evidence-based recommendations for the future delivery of the Sharing Stories for Wellbeing in palliative care.

## 3 Methods

This section outlines the approach adopted in undertaking this evaluation. A mixed method approach was chosen to achieve a comprehensive understanding of the way the Sharing Stories for Wellbeing sessions were run, their impact on participants, family members and hospice staff.

### 3.1 Patient Paper Questionnaire

A questionnaire was developed by the IoHW team and in consultation with the commissioner, to explore the views of participants prior to and after taking part in the workshops. The pre questionnaire had 19 questions and included a combination of open ended questions and 'tick box' questions, including demographic questions. The questionnaire sought to understand participants' expectations for the sharing stories programme, reasons for participation and questions to assess wellbeing (to include self-confidence, empowerment and personal and social wellbeing), based on the palliative care wellbeing questionnaires MISSOULA-VITAS® Quality Of Life Index, the POS (The Palliative Care Outcome Scale) and the Warwick and Edinburgh Mental Wellbeing Scale. The post questionnaire (13 questions) assessed the wellbeing of participants as per the questions posed on the pre questionnaire, to enable a direct pre and post comparison.

The questionnaires were distributed by staff at the hospices to participants, ensuring that no personal identifiable data was viewed or held by the IoHW team. The questionnaires were given a unique participant ID number to enable pre and post questionnaires to be linked. The post questionnaire was distributed at the end of the five week workshop sessions. Completed questionnaires were returned to the IoHW team via a freepost reply envelope.

Of the five participants who started the Story Sharing workshops, three completed the sessions, and one participant attended all five sessions. Only two completed pre questionnaires were returned and two post questionnaires (of which, half of the questions were not answered – these were on the reverse side of the questionnaire and may have been missed by the participants). As such, there was limited data to report from the pre and post questionnaires and insufficient to draw any conclusions. The findings from this stage of the evaluation are presented in the Results section.

## **3.2 Face to face Interviews with Participants**

Three interviews were undertaken with participants who had consented to take part in the evaluation. Each interview ran for approximately 30 minutes and were semi-structured interviews based on a discussion guide developed by the IoHW team, in collaboration with the commissioner. The interviews explored the experience of having participated in the workshops, how expectations were/were not met, perceived benefits of participation, what participants got out of the workshops, communication with family members and staff and suggested improvements to the process.

Interviews were arranged at a time and place to suit the participants, and were conducted at the hospice and within participant's homes. Interviews were arranged through the hospice staff.

## **3.3 Staff and Family Face to Face Interviews**

Four interviews were undertaken with a family member of a participant and with members of staff from the hospice.

Interviews were semi-structured and based on a discussion guide developed by the IoHW team, in collaboration with the commissioner. The interviews were conducted face to face and were approximately 30 minutes in duration. The interviews explored awareness of the sessions, perceived benefits of participation, communication with family members and staff, perceived changes in wellbeing and suggested improvements to the process.

All the interviews were fully audio recorded and transcribed. Transcribed data was anonymised. The Results section includes verbatim comments to exemplify emergent themes.

## **3.4 Participant Observation**

Two participant observations were undertaken, one mid-way through the workshop programme and one at the end. Observations were conducted by one member of the evaluation team and were used to gain a better understanding of the Story Sharing for Wellbeing programme, the facilitator's interactions with participants, the structure of the sessions, with particular focus on the introduction/closure to the session, engagement of

the participants and process of recording the stories. Detailed observation notes were taken during and directly after the sessions. These were written into an observation report and form part of the findings of the final report.

### **3.5 Analysis**

Data obtained via the interviews was analysed thematically, using Braun and Clarke's (2006) six steps of thematic data analysis (1. Familiarisation; 2. Generation of initial codes; 3. Searching for themes; 4. Reviewing themes; 5. Defining and naming themes; 6. Write-up of themes). Quantitative data collected from the pre-workshop questionnaire was input into the Statistical Package for the Social Sciences (SPSS) for analysis. However, due to the low number of responses it was not feasible to conduct any in-depth analysis on the data. The findings from this analysis are presented in Section 4: Results.

## 4 Research Findings

### 4.1 Pre and Post Questionnaire

Four completed pre questionnaires were returned to the IoHW research team – see Table 1 for demographic profile. Of those four individuals, three had heard about the session from staff members at the hospital and one from a district nurse.

**Table 1: Demographic Profile**

Gender		Age	
Male (No.)	Female (No.)	45-54 (No.)	75+ (No.)
1	3	1	3

The reasons provided for attending in the story sharing sessions were from 'interest', a 'love of listening and telling stories', 'because I like talking' and being invited to participate. Expectations for the session varied from wanting to 'find out how participants feel about themselves' and to 'meet/hear some interesting people'.

Three of the four individuals had already discussed their participation with friends and family.

Due to the number of responses for the post questionnaire, it has not been possible to include an analysis of the quantitative data collected in this report.

### 4.2 Observations

When approaching end of life a mixture of feelings and emotions may be experienced, from sadness and fear to an appreciation and reflection of a life lived (Kennedy, Fung & Carstensen, 2001). There has been much written to promote life story work in its many guises, to 'view the journey of life in its fullest dimensions' (Achenbaum, 2001, p. 17) and so it was in the observations of the Sharing Stories workshops at Peace Hospice in Watford. The Sharing Stories workshops were an inviting social space where life stories, reminiscences and memories could be shared with other users of hospice day care services. Each workshop, of which there were five in total, was based on a theme. The facilitators would bring in one or two items, which represented the theme and use these artefacts to begin conversation and share stories.

The first workshop to be observed was based on the theme 'colour'. Small glasses filled with chocolate Smarties were passed around, along with a prism, which when held up to the light caught the colours of the rainbow. This elicited discussion about favourite colours and the memories this invoked; the lilac of a school uniform, favoured plants, recollections of boarding school and living abroad. The facilitators listened intently, scribing the stories as they were being told and only infrequently asking open ended questions, which elicited further stories. The participants seemed delighted to share these stories with a new audience. The facilitators asked questions which included all the senses in order to elicit more detail: what did that smell like, how did that feel, can you describe how that looked? All the time the facilitators were perceived to be actively listening and appreciating the sharing of stories.

Throughout the observations there were lots of reassuring gestures from the facilitators. There seemed genuine interest in the stories; comments were made about how interesting the stories were and for the participants to not worry if they repeated themselves. There was a sense that participants valued 'being heard'. The interactions between participants and facilitators were performed sensitively and with positivity.

The stories shared during the workshops, which were observed, were mainly positioned in the past and reflected positive experiences. There was no mention of illness and very little focus on the future. In a rather poignant moment at the end of one of the sessions one participant said "I shan't have a chance to talk, [family] get a bit fed up with hearing my stories" which highlights her appreciation of the social space to share her stories with a new audience.

During the second observation, 'mirroring' stories was witnessed. One participant would recount a story to another participant who would retell the story to the group. This was a valuable technique in providing each participant the opportunity to share a story while also ensuring that each participant felt heard and valued. One of the facilitators in particular was very skilled at making the participants feel valued and identified the interesting and salient points of the story being shared. The facilitator identified positive aspects of the story telling "that says something about your determination". These promoted a positive sense of wellbeing, which could equally be applied to the participant's current illness, although this link was not made explicitly during the workshop.

During both observations, care and consideration for the participants was noted. One participant had a painful foot, so a footstool was brought in, another participant needed a more comfortable chair and this was arranged. Tea, coffee and biscuits were waiting

as was a warm welcome from the facilitators. During the observations participants seemed at ease with the process and appeared to enjoy hearing and sharing each other's stories. Generally speaking the participants seemed happy in the workshops.

A difference in style was observed between the two facilitators running the workshops, in terms of their interactions with the participants and use of stimulus material to prompt stories. It should be acknowledged that one facilitator was still in the training phase of their facilitation work. Recommendations regarding possible facilitator training are offered in the concluding section of this report.

### 4.3 Interviews

In addition to two observations, face to face interviews were conducted with staff, participants and one family member (who also participated in the workshops). Four broad themes emerged from these interviews, that of *pleasure, what makes you you, more than just a patient* and *benefits beyond the group*. Each theme is explored using quotes and contemporary literature to elucidate the points made by the participants.

#### 4.3.1 Pleasure

Pleasure from participating in the Sharing Stories workshops was evident in all the participant interviews. There was a sense of enjoyment for facilitators and participants alike.

*"It's just great fun ... yes, I enjoyed it very much"* (Clara, participant)

*"I really enjoyed it, we sat here and had coffee"* (Nora, participant)

Both Clara and Nora express pleasure in the above quotes. For Clara, Sharing Stories was fun and enjoyable, and for Nora it was the everydayness of just sitting and having coffee which was pleasant. Pleasure was found to be a core value of palliative care patients in Hack et al's (2010) qualitative analysis. The Hack et al. (2010) study reports greater life meaning when patients experience enjoyable activities, that happiness is defined within a framework of three constructs; pleasure, engagement and meaning. These constructs are evident to a greater and lesser degree within the Sharing Stories workshops.

Here Clara emphasises the work the facilitators undertake to ensure that participants have a sense of being heard.

*"Well, they [facilitators] were very good. The trouble is they don't stop me when I go off the point, they let me waffle as you probably noticed"* [laugh] (Clara, participant)

The humour with which this comment is made gives a sense of the comfortable relationship between Clara and the facilitators. Pleasure in daily activities and good human relationships are cited as important factors in coping with illness and disease by Ando, Tsuda and Morita (2007). By letting Clara 'waffle on' the facilitators engender a sense of person centred care, a genuine interest in what Clara has to say, which, Cowie (2012) argues is an important component of clinical care.

In support of the observation work undertaken in this evaluation, Nora comments here about the sensory aspects of Sharing Stories.

*"It was fascinating, the girls [facilitators] were great, both of them were great about dropping in words and were very clever about taste and smell which I found fascinating"* (Nora, participant)

Nora is taking pleasure in seeing the world in a more sensorial way. Sensory experiences were noted in Cour and Hansen's (2012) article. Cour and Hansen (2012) suggest that patients make sense of their situation by developing strategies including narrative talk, but that these experiences can be enhanced when discussed in conjunction with sensory experiences, touch and crafting in this instance. So it is interesting how Nora picks up on the sensory aspects of the Sharing Stories workshops. This is an area which may be developed further in future workshops.

In contrast to the other participants, Susan seemed a little more guarded in her participation. Here she expresses interest and pleasure in Sharing Stories, but notes that she shared only that which she was comfortable sharing.

*"Yes, I mean hearing their stories was always interesting and sharing mine was fine because I didn't tell anything I didn't want people to know"* (Susan, participant)

In this way Susan is expressing a sense of autonomy, being able to choose what she does and does not disclose is important. Ohnsorge, Gudat and Rehmann-Sutter (2014) write of the complexity of autonomy particularly for cancer care patients and that fear of losing autonomy is common among this cohort. Here Susan is highlighting her ability to make choices, an ability which perhaps she feels is lacking in other aspects of her life. Kasl-Godley, King and Quill (2014) cite autonomy as one of many losses experienced by cancer care patients. In choosing what she discloses, Susan is maintaining her sense of

self-determination and autonomy both of which are synonymous with wellbeing (Wilson, Ingleton, Gott & Gardiner, 2013).

Henry initially accompanied his wife who accessed Starlight services at Peace Hospice, but he also started to contribute to the Sharing Stories workshops and joined in with the group. He talks here of the disappointment of missing a week which covered a topic of particular interest to him.

*"The one we missed out on was the one where we were supposed to bring musical literature so we didn't actually participate in that one which was a pity because I think that actually would be a particularly valuable subject to explore"* (Henry, participant)

Musical literature seems to be a topic which Henry would have particularly enjoyed exploring with the group. Group attendance was sporadic, either due to a clash with other plans or stays in hospital, but it would appear from this quote that these sessions were missed when attendance was not possible.

Pleasure was also experienced by the facilitators. here Lisa talks of the positive impact attending the group has had for her and the feedback she received from participants.

*"...just meeting up with people and very interesting people and it's just nice to meet up and share and very enjoyable, yeah... I think they [participants] are wonderful, I'd like to think there are going to be more of them [Sharing Stories workshops] and I just think they are very, very beneficial and I think people, I know because their feedback has been that they have really, really enjoyed coming, you know to the sessions"* (Lisa, Hospice staff)

Kabel (2013) argues that palliative care has broadened its services to accommodate patients who are in the earlier stages of illness and that the day care model allows patients to "participate in the social world" (p. 148). This is being demonstrated in the Sharing Stories workshops. Lisa is expressing her delight at meeting new and interesting people and enjoying their stories. This kind of meaningful engagement is identified as having a positive effect on wellbeing (Kabel, 2013). This mutual pleasure between the facilitator and the participants enables a comfortable social space for Sharing Stories. Rodin (2013) offers evidence that early palliative care intervention has positive effects in engaging with patients and that spiritual wellbeing is affected by not only religious or other beliefs but also by self-esteem and a sense of relatedness which could be promoted in such groups as Sharing Stories. This can be seen in the following quote from Henry:

*"I mean what I was beginning to find and particularly with [another participant] what we were finding was we had lots in common, particularly with the war and post war years."* (Henry, participant)

In conclusion, this theme demonstrates that pleasure was a central aspect of the Sharing Stories workshops, as expressed by both facilitators and participants, verbally and non-verbally, when referring to the workshops. This theme highlights the importance of getting together and creating a social space where stories can be shared. The theme feeds into a sense of autonomy and self-determination as participants chose what stories to share with the group. None of the participants expressed any particular problem or issue with the Sharing Stories workshops, although it was reported the one participant only attended the first meeting and declined to attend any further meetings. It was explained that this particular participant had wanted to attend a creative writing skills session to inspire their own writing. While this individual had enjoyed the session, they had not found the format of the session helpful in developing their own writing skills.

#### *4.3.2 What makes you You*

The second theme to emerge from the data focuses on what is important in the lives of participants, what moments have shaped and given meaning to their lived experience. As Cowie (2012) suggests 'clinicians should learn to ask not only 'what is the matter?', but 'what matters?'" This seems essential to understanding the person not 'as a dying patient with no future rather than as living persons with a limited future' (de Lange, 2013, p. 515). Here participants talk of the importance of looking back and remembering significant events. Clara recounts her experience of rationing in this next quote:

*"I think it's important because an awful lot of things we've experienced will be gone, all sorts of things from the food and... Well you think some things were only available to blue ration book people that was up to 16 and if you saw a queue outside the greengrocers you joined it, you didn't know what you were getting but... We only went on Saturday, we collected our rations of sweets on a Saturday and my mother would dole them out through the week."* (Clara, participant)

Clara expresses here the sense of importance that she shares the experiences she has because soon they/she will be gone. These comments support Erikson's (1969) developmental phase of generativity which Erikson suggests is the 'concern of establishing and guiding the next generation' (p. 258). This sense of leaving knowledge behind or passing experiences on is also present in contemporary literature (Ando, Tsuda

& Morita, 2007; Cour & Hansen, 2012; Redhouse, 2014; Xiao, Kwong, Pang & Mok, 2011).

*"Well I suppose personally you think about things that you haven't thought about in a long time and that gives you some pleasure and as you say you can pass them onto future generations of the family."* (Clara, participant)

Again, Clara speaks later in the interview of the desire to 'pass [her stories] onto future generations of the family'. These comments echo those found by Redhouse (2014) where her participant 'Iris' talked of 'wanting to provide insight into 'the way things used to be' and being known as 'more than just a grandmother' (p. 78).

Here Susan recounts a significant, epiphanic event in her life, that of a book she was involved in the production of which subsequently changed her life course.

*"Well yes because this book that I brought it [was] written by the doctors [and] changed my whole outlook on life I stopped being a secretary and went to college and did a degree in life sciences so it was very life changing and enhancing"* (Susan, participant)

The role of reminiscing about past achievements and reliving good (and not so good) memories are cited as important aspects of Sharing Stories work (Ando, Tsuda & Morita, 2007; Xiao, Kwong, Pang & Mok, 2011). This is reflected in Susan's husband's interview as he talks about the benefits of attending the Sharing Stories workshops for Susan.

*"Yes, I think so and I mean I thought she actually engaged quite well with the sorts of discussions and it did enable her to bring out quite important things in her life, yes"* (Henry, participant)

From these comments comes a sense of improved wellbeing for Susan, having that social space to express events which were important in her life. The recognition and desire to create this social space is seen in the facilitator and staff comments also. Here Lisa acknowledges the skills of facilitation and how this impacts positively for participants.

*"Well Miranda who set the whole thing up she has got such wonderful ideas she's got such a creative way about her she just flows, she's amazing. It's just very powerful, really powerful and what's amazing, it's not our story it's their story and what we are doing it just listening and we are writing it down so they can have amazing stories that they can have back and do what they want with. I mean*

*hopefully they share it with family but even if they don't that is a big part of them and I think that is important"* (Lisa, Hospice staff)

Most narrative based therapies strive to help participants to find hope, purpose and meaning even in difficult situations. However, as Lisa states here, even if new meaning is not found or knowledge is not shared just taking part in the workshops decreases social isolation (Kasl-Godley, King & Quill, 2014). Just 'getting out and about and doing something' was a thread which ran through all patient interviews.

For some participants, it was the relational aspects of their reminiscences which were most important. Here Nora talks about how the facilitators used the sensory information regarding her experience of the war, which in turn triggered memories of people she had not thought about for decades.

*"To get people started, what smell do you remember from the war and what taste. It was amazing what it brought back, it was absolutely fascinating and so many things came out that you'd completely forgotten... I remembered things I had completely forgotten and it was good because you remembered people you were fond of and hadn't thought about you know for sixty years and it's good to do that"* (Nora, participant)

Nora acknowledges the positive benefits – 'you remembered people you were fond of... it's good to do that' – of taking part in the workshops. Ando, Tsuda & Morita (2007) state that 'patients who have good human relationships do not feel lonely and can act as support systems for others' (p. 229). Arguably, reflecting on the positive relationships with people who were emotionally significant promotes wellbeing. This sense of looking back at past achievements and leaving some personal experiential knowledge should be an aim of the workshops, according to Ann who is a member of staff at Peace Hospice.

*"But I think it's just an important fact for people who are facing death whether that be six months or a year that you start thinking about what has my life been about, what was the point, what have I achieved, what have I done and what am I leaving behind and I think it's more for that person perhaps than the next generation, at that point. But like you said you get to middle age and you think I don't know anything about great granddad and there are no stories to be told"* (Ann, Hospice staff)

This life review approach is supported by current literature as being of positive benefit for many palliative care patients. Ando, Tsuda & Morita (2007) suggest that life review work incorporates looking back at good and bad memories and events, paying particular

attention to positive aspects of significant life events, rekindling past passions and pastimes and remembering good relationships and forging new ones. Ohnsorge, Gudat and Rehmann-Sutter (2014) offer a more narrative model which advocates self-understanding, linking life events and summarising important aspects. Whereas, Hack, et al. (2010) suggest a more therapeutic approach exploring meaning and experiencing 'being in the world' and Redhouse (2014) uses drama therapy as a means of co-constructing a life review with a patient. Evidence is offered that suggests these various approaches can have positive benefits on wellbeing for palliative care patients. However, the skills required to run such reviews may require specific training and/or a therapeutic background.

### *4.3.3 More than just a patient*

The theme *more than just a patient* runs across the interviews. Barnes and Mercer (2003) write of the re-evaluation of identity needed when faced with chronic illness or disability and this need to be identified as a person beyond their patient status is seen in some of the following comments. While there is a need to be identified as a person beyond the patient status, the following comment from Clara exemplifies the way the patient status can take priority:

*"Well yes I've got nothing else to do apart from medical appointments"* (Clara, participant)

There is a sense in Clara's quote that her existence has been metered down to just hospital appointments, which is in contrast to the delight she clearly showed when taking part in the Sharing Stories workshops and evaluation interview. Perhaps this quote is even more poignant as it was Clara who felt her family were fed up with hearing her stories (mentioned in the observation section). She also explained that she was unable to drive at the moment or walk very far even with support so found her daily existence increasingly restricted. Here Nora makes reference to a pastime she enjoyed before she was ill and how the Sharing Stories group inspired her to bake again:

*"We had a, the first time we were talking about cooking and before I was ill I made cakes for everybody so I said "right I'll bring in one of my best Victoria sandwiches next week" so we all sat round and had cake."* (Nora, participant)

The Sharing Stories workshop has rekindled her previous hobby (Ando, Tsuda & Morita, 2007) and given Nora a sense of purpose; to bake for others (Kasl-Godley, King & Quill, 2014). By baking again, it could be argued that Nora is regaining some control and

shifting her identity back to her former self (Ohnsorge, Gudat & Rehmann-Sutter, 2014). Here Susan is also looking back to an earlier time before illness:

*"Well I think it made one think and recollect things and certainly I found that mine brought back memories and I presume that it did for everyone... Because I think one tends to forget ones earlier life and it's good not to forget so...."* (Susan, participant)

Kabel (2013) argues that hospice day care plays a vital role in staving off the label of 'full-time patient' for as long as possible. She suggests that day care promotes a sense of normality, social identity and 'an opportunity to step outside of their patienthood' (p. 153). These meaningful engagements enable a broader life focus than that which a diagnosis can bring.

Nora demonstrates really well in this next quote how much she misses her professional life and the social connections which that brought:

*"I'm bored at the moment I'll do anything because you know I worked until I was 75 and I was a practice nurse then so I've always been with people and I find not being with people very dull"* (Nora, participant)

Here Nora talks not of the difficulty of living with her illness, but the difficulty of not being with people. As Dame Cicely Saunders, the founder of the hospice movement in the UK wrote, 'you matter because of who you are. You matter to the last moment of your life, and we will do all we can, not only to help you die peacefully, but also to live until you die' (cited in LaPointe & Allen, 2015). This seems a particularly apt quote to use within this theme. These participants want to be viewed as more than just a patient, but as a person with a vibrant and vital history, desires, interests and needs.

This need to be seen as more than just a patient was reflected in the supporting staff who worked with the Sharing Stories participants. Here Christine describes the feedback from one of her patients when talking about the Sharing Stories workshops:

*"One of my patients has said she felt she was a bit more individual again, a bit more in control because she was actually telling people about her life story.... So she felt she was doing something worthwhile. That's what she described it as and she felt humble because other people were interested in it, because other group members were asking her about it."* (Christine, Hospice staff)

Christine talks about how her patient was beginning to see herself as an individual again, with a sense of autonomy. But beyond that there is a sense of feeling valued and having

a purpose. There is a sense of the cyclical nature of the benefits here; people are interested so you gain more confidence to share more stories which engender feelings of self-worth. These positive benefits are also identified by Lisa who facilitates some of the workshops:

*"Absolutely and being included and when you are actually talking and you're being heard you are feeling like, you know....."* (Lisa, Hospice staff)

*"Like you still matter?"* (Researcher)

*"Yeah."* (Lisa, Hospice staff)

Active listening is cited by Nelson-Jones (2003) as a vital skill in any helping relationship, but also acknowledges that this is frequently lacking in our busy lives. We do not always have the time or the patience for intense, active listening. The mirroring element of the Sharing Stories workshops was a particularly useful tool for ensuring active listening.

Ann also understands the importance of seeing the person beyond the illness as can be seen in the following comment:

*"And of course a lot of our patients have had such interesting lives they get to a point particularly the older ones that suddenly none of that matters anymore and we don't see that, all we see is a person with cancer or person with this or a person with that and they lose that identity and I think there is a lot more we could do"* (Ann, Hospice staff)

Gott, et al. (2011) argues that a multi-disciplinary model of care is necessary in palliative care and that everyone needs to take responsibility for patient care. The Sharing Stories workshops are an ideal opportunity to engage staff and patients alike in a project which can enable 'identity maintenance' in an enjoyable way (Coleman, 1990).

#### *4.3.4 Benefits beyond the group*

In the final theme to emerge from the interview, the participants talk of benefits beyond that of attending the Sharing Stories workshops. Staff and patients talk of how the interest gained as part of the Sharing Stories workshops has developed into other aspects of their lives. Here, Christine talks of a patient who has increased in confidence as a result of attending the Sharing Stories workshops, this has enabled her to access other groups:

*"I don't think she's different, it may have boosted her confidence a little bit. I think maybe. She's doing something else now, she's doing another group and she's meeting more people and that's another social networking, way of, friendship bonding and feeling more confident in yourself. I think she thinks I can do this and if I don't like it, I don't like it but she did like it because there was nobody really that she knew in that group so it's quite nice. I think when you come to the groups after a time you get quite comfortable which is good but then it's other times you get them to move on and do something different as well."*  
(Christine, Hospice staff)

Trying new things is cited as having a positive effect on wellbeing (Kabel, 2013; Kasl-Godley, King & Quill, 2014). By attending the Sharing Stories workshops, Christine's patient was able to feel more confident about accessing other groups. Rodin (2013) argues for the early intervention of palliative care and the positive benefits of this, for example, trying new experiences, reduction in social isolation and remaining active are seen within this theme.

The importance of social interaction is also seen in Nora's narrative. Nora was a particularly sociable person and her quiet reflection expresses a sadness as to the loss of social contact she found through her working life. However, she also reflects that the workshops have helped her to acknowledge the achievements she has experienced in her life:

*"But what I've really enjoyed most is meeting different people because at this age, once you stop working, which I hated.... I think you miss that terribly and so you sit on the thing and think about it for a while and think well at least I did something with my life"* (Nora, participant)

The principles of person centred care developed by Kitwood (1997), predominantly in the field of dementia care but arguably just as relevant to all care, challenged traditional notions of care by suggesting that the person should come first, over and above the diagnosis. He called into question the paternalistic, ageist, medical model which had, and arguably still does, dominate aged care. To apply the person centred care model to Nora would be to recognise her former long nursing career and her need to feel valued by others.

Henry saw positive aspects of the Sharing Stories workshops in terms of wellbeing for his wife, Susan. He felt she was able to step away from her difficulties and focus her mind in more positive ways:

*"Yes, I think that's probably fair yes and probably helped her in the sense that its enabled her to step away from the current problems that she's got and look back in more positive ways at what she has achieved, yes" (Henry, participant)*

This was important for Susan as, as Henry explained, she had been through quite difficult treatment in the last year which had affected her personality. Henry talked about how Susan had previously been very outgoing but had explained that "with her condition being what it is she is not in a terribly positive frame of mind at the moment". With this in mind some respite from her illness, however transitory, is welcome. Henry is appreciative that the Sharing Stories workshops offer this.

*Benefits beyond the group* also extended beyond sharing stories. Here Nora and Lisa comment on the importance of sharing other skills, that of cooking. Nora talks here of exchanging recipe ideas with Henry during one session:

*"We hit it off....we were swapping food because he does the cooking" (Nora, participant)*

Whilst Lisa talks of how she followed one of Nora's recipes to bake a cake for her family:

*"And this lovely lady had told us the week before that she loved baking and so bought in a cake which was amazing and I actually made the cake [laugh] for my family on the weekend and they loved it and I took a photo to show her but sadly she was in hospital last week so I'm really hoping she is here today because we miss her, she is really good fun and a very interesting lady." (Lisa, Hospice staff)*

For Lisa and Nora baking and sharing recipes are important aspects of caring for others. This interaction between participants and staff promote the sense of social bonding, a space for connection with others and a means of being in the world as an authentic self (Cour & Hansen, 2012; Kabel, 2013; Redhouse, 2014), arguably all qualities which promote a sense of positive wellbeing.

## 5 Conclusion and Recommendations

The Sharing Stories workshops created a friendly, relaxed social space for participants to engage in storytelling. The workshops ran for five consecutive weeks which seems short when compared to similar groups; Rodin (2013) recommends eight week sessions. Longer sessions would enable participants, such as Nora who was admitted to hospital for three weeks after only two sessions, to engage with the process for longer.

The Sharing Stories project needs to be clear in its aims and objectives. There is scope for a more life review focus to these workshops, although this approach may require a more therapeutic focus for which additional training would be needed for facilitators. Training should include person centred awareness and practice, understanding storytelling and basic counselling skills such as giving voice, inclusion, enabling, respect and active listening.

Once the aims and objectives of this group have been decided, this information should be disseminated to staff across the hospice so that potential participants can be informed and the remit of the group explained. Depending on the aims of the group, group size should be kept to a maximum of 6 or 7 participants. A life review model works best when performed in one-to-one sessions.

During the course of the Sharing Stories workshops, facilitators took notes which detailed the stories being told. These notes were then typed up, sometimes with photos and pictures from the internet and presented to the participant the following week. There is potentially much broader scope available here. Redhouse (2014) talks of the creation of a life story book for grandchildren in her drama therapy work. There is a sense that rather than individual stories being handed over each week, that they could be gathered together and presented in a more formal way, as a 'cultural artefact' (Redhouse, 2014, p. 78), such as in a life story book or folder. There is also scope for stories to be taken down in different form, the use of voice recording or full transcription to really embody a sense of the storyteller. However, these are time consuming tasks and may require specialist recording equipment or software.

The themes to emerge engender a sense of positive wellbeing for those who took part and this evaluation found participants not only enjoyed the sessions but found value in attending. Participants were given a sense of autonomy and control in what they shared with the group and found the sessions provided a social occasion where they could share similar interests and enjoy a sense of togetherness. The sessions also provided a way to explore their self-identity, to be valued as a person and not just as a patient.

Furthermore the telling of their stories, being able to reminisce about their lives brought reminders of changing times and of lived experiences which were respected and shared with others. Taking part in the Story Sharing workshops also led participants to explore new activities, with some experiencing improved confidence and reduced social isolation.

There are many opportunities to create various groups based on storytelling, women/men only groups, groups who incorporate craft or gardening with storytelling, life review, dignity therapy, narrative therapy and so on. Provided that sufficient safeguards are in place for both participants and facilitators to manage difficult disclosures, storytelling would appear to have a positive effect on wellbeing in a palliative care setting.

## **5.1 Recommendations**

The following recommendations are made for future consideration of the development of the workshops and training for new facilitators.

Ensure that the workshops are clear about their purpose and what taking part will mean, with the aim to avoid any confusion and promote participation. Ensure that staff are familiar with the aims and objectives of the group, also enabling them to better inform patients about the workshops and increase participation.

The enthusiasm and belief in the Sharing Stories workshops is evident from Starlight staff, facilitators and participants. However, there is scope for more in-depth life review work within this project which may prove to promote a greater sense of wellbeing for participants. A clear set of objectives for these workshops needs to be drawn up to provide a framework for future sessions.

Consideration to be given to the number of sessions delivered. The current five sessions could be extended to eight to allow for greater engagement with the process. Additionally, the use of recording and transcription of the sessions may provide an added element to the stories provided to the participants, with their stories retold verbatim.

Giving back the stories to the participants is an important element of the Sharing Stories workshops, the development of a life story 'book' or folder could be developed and provided to participants at the end of the workshops. While checking the accuracy of the stories during the workshops is important, a final 'book' could also provide a celebratory end to the sessions.

Whilst patient status is important for treatment and pain management, seeing beyond the illness is an important aspect of care for participants. The inclusion of a person centred approach embodied in palliative care giving would be an important addition to future training of workshop facilitators.

## References

Abma, T.A. (2003) Learning by telling, storytelling workshops as an organisational learning intervention. *Management Learning*, 34(4), 221-240.

Achenbaum, A. W. (2001). The flow of spiritual time amid the tides of life. In S. H. McFadden and R. C. Atchley [Eds.]. *Aging and the Meaning of Time*. (Ch. 1). New York: Springer.

Ando, M., Tsuda, A., & Morita, T. (2007). Life review interviews on the spiritual well-being of terminally ill cancer patients. *Support Care Cancer*, 15, 225-231.

Barnes, C. & Mercer, G. (2003). *Disability*. Cambridge: Polity Press.

Coleman, P. (1990). Adjustment in later life. In J. Bond and P. Coleman (Eds.). *Ageing in Society*. London: Sage Publications.

Cowie, M. R. (2012). Person-centred care: more than just improving patient satisfaction. *European Heart Journal*, 33, 1037-1039.

Cour K., & Hansen, H. P. (2012). Aesthetic engagements: "Being" in everyday life with advanced cancer. *American Journal of Hospice & Palliative Medicine*, 29, (2), 126-133.

De Jong, J. D. and Clarke, L.E.(2009) What is a good death? Stories from palliative care. *Journal of Palliative Care*, 25(1), 61-67.

De Lange, D. F. (2014). Affirming life in the face of death: Ricoeur's living up to death as a modern ars moriendi and a lesson for palliative care. *Medical Health Care and Philosophy*, 17, 509-518.

Erikson, E. H. (1969). *Childhood and Society*. Middlesex: Penguin.

Frank, A (2010) *Letting Stories Breathe: A Socio-Narratology*.

Gott, M., Seymour, J., Ingleton, C., Gardiner, C. & Bellamy, G. (2011). 'That's part of everybody's job: the perspectives of health care staff in England and New Zealand on the meaning and remit of palliative care. *Palliative Medicine*, 26, (3), 232-241.

Hack, T. F., McClement, S. E., Chochinov, H. M., Cann, B. J., Hassard, T. H., Kristjanson, L. J., & Harlos, M. (2010). Learning from dying patients during their final days: life reflections gleaned from dignity therapy. *Palliative Medicine*, 24, (7), 715-723.

Heggestad, A.K.T. and Slettebø, A. (2015) How individuals with dementia in nursing homes maintain their dignity through life storytelling – a case study. *Journal of Clinical Nursing*, 24, 2323-2330.

Heiney, S. P., Darr-Hope, H., Meriwether, M.P. and Adams, S.A. (2015) Healing by creating: patient evaluations of art-making program. *Journal of Creative Behaviour*.

Holm, A-K., Lepp, M. and Ringsberg, K. C. (2005) Dementia: involving patients in storytelling – a caring intervention. A pilot study. *Journal of Clinical Nursing*, 14(2), 256-263.

Kabel, A. (2013). The Snog and Grog club: Social personhood in hospice care. *Qualitative Health Research*, 23, (2), 147-155.

Kasl-Godley, J. E., King, D. A., & Quill, T. E. (2014). Opportunities for psychologists in palliative care: Working with patients and families across the disease continuum. *American Psychologist*, 69, (4), 364-376.

Kennedy, Q., Fung, H. H., & Carstensen, L. L. (2001). Aging, time, estimation, and emotion. In S. H. McFadden and R. C. Atchley [Eds.]. *Aging and the Meaning of Time*. (Ch. 3). New York: Springer.

Kitwood, T. (1997). *Dementia Reconsidered*. Maidenhead: Open University Press.

Konner, M. (2010) *The Evolution of Childhood Relationships, Emotion, Mind*. Harvard University Press.

LaPointe, B. J. & Allen, D. (2015). Hospital-based palliative care. In J. M. Stillion and T. Attig [Eds.]. *Death, Dying and Bereavement: Contemporary Perspectives, Institutions and Practices*. (Ch. 11). New York: Springer.

Nadeau, J.W. (1998) *Families Making Sense of Death*. Thousand Oaks, California: Sage.

Nadeau, J.W. (2001) Family construction of meaning. In: Neimeyer RA, ed. *Meaning Reconstruction and the Experience of Loss*. Washington, DC: American Psychological Association; 2001:95-112.

Nelson-Jones, R. (2003). *Basic Counselling Skills*. London: Sage Publications.

Ohnsorge, K., Gudat, H., & Rehmann-Sutter, C. (2014). What a wish to die can mean: reasons, meanings and functions of wishes to die, reported from 30 qualitative case

studies of terminally ill cancer patients in palliative care. *BMC Palliative Care*, 13, 38, 1-14.

Ransom, A (2012) *A History of Story-Telling: Studies in the Development of Narrative* (Classic Reprint). Hong Kong: Forgotten Books.

Redhouse, R. (2014). Life-story; meaning making through dramatherapy in a palliative care context. *Dramatherapy*, 36, (2-3), 66-80.

Rodin, G. (2013). Research on psychological and social factors in palliative care: An invited commentary. *Palliative Medicine*, 27, (10), 925-931.

Romanoff, B.D. and Thompson, B.E. (2006) Meaning construction in palliative care: the use of narrative, ritual, and the expressive arts. *American Journal of Hospice & Palliative Medicine*, 23(4), 309-316.

Synnes, O. (2015) Narratives of nostalgia in the face of death: the importance of lighter stories of the past in palliative care. *Journal of Aging Studies*, 34, 169-176.

Wilson, F., Ingleton, C., Gott, M., & Gardiner, C. (2013). Autonomy and choice in palliative care: time for a new model? *Journal of Advanced Nursing*, 70, (5), 1020-1029.

Xiao, H., Kwong, E., Pang, S. & Mok, E. (2011). Perceptions of a life review programmes among Chinese patients with advanced cancer. *Journal of Clinical Nursing*, 21, 564-572.



Report compiled by:

Institute of Health and Wellbeing

The University of Northampton  
Boughton Green Road  
Northampton NN2 7AL

Tel: (01606) 892887