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Title: Supporting wellbeing for people in palliative care: the role of sharing stories for wellbeing life story workshops

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Example citation: Youell, J., Ward, A. and Quinney, M. (2016) Supporting wellbeing for people in palliative care: the role of sharing stories for wellbeing life story workshops. In: Davidson, J. and Saber, Y. (eds.) *Narrating Illness: Prospects and Constraints*. Oxford: Inter-Disciplinary Press.

It is advisable to refer to the publisher's version if you intend to cite from this work.

Version: Accepted version

Official URL: <http://www.interdisciplinarypress.net/product/narrating-illness-prospects-and-constraints/>

Note: A version of this article originally appeared in *Narrating Illness: Prospects and Constraints* (2016), first published by the Inter-Disciplinary Press.

<http://nectar.northampton.ac.uk/8581/>



Title – Supporting wellbeing for people in palliative care: The role of Sharing Stories for Wellbeing life story workshops.

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Declaration of Interest: The project was funded by Peace Hospice Care and Hospice of St Francis.

Acknowledgements: The research team would like to thank Peach Hospice Care and Hospice of St Francis for their support with this evaluation and Doreen Pattenson, senior social worker and consultant to the project without whom Sharing Stories for Wellbeing would not have been able to get started.

Word count: 2989

Abstract

Background

Sharing Stories for Wellbeing (SS4WB) (2011), provides facilitated storytelling sessions in palliative care. Workshops foster life-story discussions which participants share with the group, these are delivered in a non-linear style and are based on themed topics (seasons/colours). Groups are supported by hospice staff, who provide pastoral/professional care. Informal observational feedback suggested potential benefits for participants were improved self-esteem, feelings of being valued and listened to at a time of personal distress. The running of new SS4WB sessions gave the opportunity to conduct a formal evaluation and to understand the potential value of participation.

Method

The evaluation, run by the University of Northampton, was conducted over five weekly sessions run at a UK hospice (May-June 2015). Sessions were attended by five people receiving palliative care. A mixed method approach used participant observations (n=2), face-to-face interviews with hospice staff (n=3), family members (n=1) and participants (n=3).

Results

Four broad evaluation themes emerged: 'pleasure'; 'what makes you you'; 'more than just a patient'; 'benefits beyond the group'. Participants reported enjoyment and felt a sense of autonomy and control in deciding on the stories shared. Sessions provided an opportunity for social engagement, giving a sense of togetherness and were a means to explore their sense of self and feel valued as a person not a patient. The telling of biographical reminiscences was reported to bring positive reminders of changing times and lived experiences. Workshop engagement led some participants to experience improved confidence and reduced social isolation, evidenced through staff and family views and participation in new activities.

Conclusion

SS4WB enables people in palliative care to share their life-stories in a supportive and safe environment. Participation can have positive outcomes fostering choice in the stories shared which engender a sense of autonomy and control, reminiscences can also bring feelings of value and self-esteem.

Introduction

As humans we 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; Ransom, 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 add to the 'collective'. Romanoff & Thompson (2006) 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, saw this as an opportunity for people to 'communicate experiences, relate stories to each other and collaboratively create meaning' (p.223).

The process of engaging in storytelling workshops incorporates both telling your story and listening to other people's, providing a 'search for knowledge, [and] understanding' (Abma, 2003, 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).

Encouraging patients to reflect on and share their life stories has been a central aim of The Sharing Stories for Wellbeing (SS4WB) project, which was set up by a storyteller and biographer in 2011. Facilitated group workshops are run in a hospice, where participants share stories, which are captured by a facilitator to be reproduced in written form and 'gifted' to the participant to keep and share. Sessions are delivered in a non-linear style and are based on themes (seasons/colours). The central objectives of SS4WB are a) to recount and record patient's 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 are promoted as 'an opportunity to capture and record your own life stories – anecdotes, words of wisdom, reminiscences and experiences'. Informal SS4WB patient feedback has found feelings of being valued and positive impact of being listened to at a time of great personal distress. Patients have referred to the story sharing process as one which has helped them to resume control over their lives and rebuild self-confidence, and self-esteem (Quinney, 2015).

An evaluation of SS4WB was conducted for a new cohort attending weekly sessions at a hospice in the north of London, UK. This evaluation was timely in providing further insight into the role of SS4WB sessions for people in palliative care and understanding its impact on participants and staff. The evaluation was based on a five-weekly programme run in May-June 2015.

Method

A mixed method design was developed, using participant questionnaires, patient and staff interviews and observations. This paper presents the findings from the qualitative elements of the study.

Semi-structured interviews were carried out with patients (n=3) and staff (n=3) and a family member (n=1). The interviews explored the experience of having participated in the workshops. Interviews were conducted either at the hospice or within the patient's home and all interviews were arranged through the hospice staff. The interviews were audio recorded and transcribed. Participant observations (n=2) were undertaken, were conducted by one member of the evaluation team and were used to gain an understanding of the SS4WB programme (interactions, structure and participant engagement). Detailed observation notes were taken during and directly after the sessions, which were written into an observation report.

Transcribed and anonymised interview data was uploaded to NVivo v.10 software and analysed thematically, using Braun and Clarke's (2006) six-steps of thematic data analysis. Appropriate ethical approval was granted through the School of Health Ethical Review Committee at the University of Northampton, with informed consent obtained from all participants at the outset of the project.

Results

Four broad themes emerged: 'pleasure', 'what makes you you', 'more than just a patient' and 'benefits beyond the group'.

Pleasure

Pleasure from SS4WB was evident in all the participant and staff interviews. The sessions were fun and enjoyable.

"It's just great fun ... yes, I enjoyed it very much" (participant 1)

"I really enjoyed it, we sat here and had coffee" (participant 2)

The role of the facilitator within the process was also emphasised by participants, who commented that they enabled participants to be heard and listened to and provided a safe and supportive environment.

"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" (participant 1)

The humour within this comment gives a sense of the comfortable relationship between participants and facilitators. This relationship and the facilitator's skills at making participants feel valued were noted in the observations. Participants also spoke of the facilitators' skill to weave different storytelling techniques into the sessions, such as using the senses or mirroring to elicit memories and enable layers of memory to unfold. This participant talks of how sensory triggers brought back experiences of the war, which in turn triggered memories of people not thought about for decades.

"To get people started, what smell do you remember... what taste. It was amazing what it brought back, it was absolutely fascinating and so many things came out that you'd completely forgotten... it was good because you remembered people you were fond of and hadn't thought about... for sixty years and it's good to do that" (participant 2)

Although participants were encouraged to share stories, it was observed they only shared what they were comfortable sharing. One participant discussed this story ownership and so shows a sense of autonomy, being able to choose what to disclose.

"...hearing their stories was always interesting and sharing mine was fine because I didn't tell anything I didn't want people to know" (participant 3)

Pleasure was also experienced by the facilitators and hospice staff, one staff member talks of the positive impact attending the group has had for her and the feedback received from participants.

"...just meeting ...very interesting people and it's just nice to meet up and share... I think they [participants] are wonderful, I'd like to think there are going to be more of them [SS4WB workshops] and I just think they are very, very beneficial ...because their feedback has been that they have really, really enjoyed coming..."
(Hospice staff 1)

Meeting new people and sharing stories also brings with it shared experiences and interests, supporting the way that those engaged in SS4WB can relate to each other and connect.

"I mean what I was beginning to find and particularly with [another participant] what we were finding was we had lots in common..." (participant 4)

What makes you You

The focus is on what is important in participant's lives, what moments have shaped and given meaning to their lived experience. The value of sharing stories was not just in reminiscing about past events but also the desire to 'pass [stories] onto future generations of the family'. The skill of the facilitator is important here in being able to both record the stories and encourage their telling:

"[facilitator] ...she has got such wonderful ideas... such a creative way about her she just flows, she's amazing. It's just very powerful, ...it's not our story it's their story and what we are doing is 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" (Hospice staff 1)

SS4WB has a dual role of sharing one's story and enabling reminiscence. Being able to reminisce both the good and perhaps not so good aspects of life's experiences was valued by participants, as one family member stated of his wife, '...she actually engaged quite well... and it did enable her to bring out quite important things in her life'. Furthermore, it could be that having the social space to discuss important aspects of one's life could lead to a sense of accomplishment and self-worth, even if new meaning is not found or knowledge is not shared. The act of taking part and 'getting out and about and doing something' was a thread which ran through all patient interviews.

More than just a patient

Participants spoke of the value of being seen as more than just a patient but also expressed how the patient identity can become the main focus, as one participant explained:

"...I've got nothing else to do apart from medical appointments" (participant 1)

A member of staff echoes the way the patient identity can overshadow the whole person. Recognising the person beyond the illness is both important and difficult to do.

"...a lot of our patients have had such interesting lives they get to a point... that suddenly none of that matters anymore and we don't see that, all we see is a person with cancer... and they lose that identity and I think there is a lot more we could do" (Hospice staff 2)

Other participants talked of former professional lives and of hobbies which are important in defining their identity. One participant makes reference to a pastime enjoyed before becoming ill and how SS4WB inspired her to bake again and consider her identity beyond that of the patient:

"...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." (participant 2)

This need to be seen as more than just a patient was reflected in staff supporting SS4WB participants. One member of staff describes the feedback from one of her patients when talking about the workshops:

"...she felt she was a bit more individual again, a bit more in control because she was actually telling people about her life story... 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." (Hospice staff 3)

The patient was beginning to see herself as an individual again, with a sense of autonomy, of feeling valued, of 'being heard' 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.

Benefits beyond the group

Participants and staff talked of benefits beyond SS4WB, of developing interests in other aspects of their lives and of developing social networks.

"She's [participant] 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." (Hospice staff 3)

"But what I've really enjoyed most is meeting different people..." (participant 2)

Discussion

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 *et al.*, 2001). Achenbaum (2001) write that it offers an opportunity to 'view the journey of life in its fullest dimensions' (p.17) and so it was in evaluating SS4WB, which offers this opportunity for reflection in a safe and supported way with skilled facilitators.

Pleasure was identified as a core value of palliative care by patients (Hack *et al.*, 2010), and was similarly explored in the SS4WB evaluation. Hack *et al.* (2010) report greater life meaning when patients experience enjoyable activities and define happiness within a framework of three constructs: pleasure, engagement and meaning. These constructs are evident to a greater and lesser degree within SS4WB as can be seen from the enjoyment of the sessions, valuing not only the storytelling but social aspects too.

Pleasure in daily activities and good human relationships are cited as important factors in coping with illness and disease (Ando *et al.*, 2007). In the example of letting a participant 'waffle on' the facilitators engender a sense of person-centred care, a genuine interest in what they have to say, which, Cowie (2012) argues is an important component of clinical care. Cowie 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). The principles of person-centred care developed by Kitwood (1997) challenged traditional notions of care by suggesting the person should come first, over and above the diagnosis. 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, suggesting that day care promotes a sense of normality, social identity and 'an opportunity to step outside of their patienthood' (p.153). SS4WB encourages this stepping out of the patient role to look at life's accomplishments, allowing the patient to see themselves differently and for staff to see the person beyond the illness. 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' (LaPointe & Allen, 2015). This seems particularly apt for SS4WB, where 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.

Kabel (2013) argues that palliative care has broadened its services to accommodate patients who are in the earlier stages of illness and the day care model allows patients to "participate in the social world" (p.148). This is being demonstrated in SS4WB, staff expressed their 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 SS4WB. 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 SS4WB. Wellbeing may

also be supported through ownership and choice. 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. In SS4WB participants identified their ability to make choices, an ability which perhaps could be lacking in other aspects of their life. Kasl-Godley *et al.* (2014) cite autonomy as one of many losses experienced by cancer care patients. So in choosing what can be disclosed, SS4WB participants are able to maintain a sense of self-determination and autonomy both of which are synonymous with wellbeing (Wilson *et al.*, 2013).

Wellbeing, it is argued, can also be supported through meaningful activity (Roland & Chappell, 2015). Phinney (2006) suggests that being engaged in the world is central to meaningful activity and is entwined with maintaining personal relationships. While Travers *et al.* (2015) suggest that meaning is derived from individualised and tailored activities. SS4WB offers participants meaning through enjoyment, personalised activity and social engagement. Additionally, taking part in the workshops decreases social isolation (Kasl-Godley *et al.*, 2014). Just 'getting out and about and doing something' was expressed in all patient interviews.

Meaning was also found in common interests, such as baking. This interaction between participants and staff promoted 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 and purpose (Kasl-Godley *et al.*, 2014). By baking again, it could be argued that the patient is regaining some control and shifting their identity back to their former self (Ohnsorge *et al.*, 2014).

The value of sharing personal stories was not just in strengthening social bonds within the group but provided an opportunity to reminisce about past events and potentially to 'pass [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). The role of reminiscing about past achievements and reliving good (and not so good) memories are cited as important aspects of life story work (Ando *et al.*, 2007; Xiao *et al.*, 2011) and is evident in SS4WB.

Conclusion

SS4WB operates on a number of different levels and principals. It takes the premise that people in palliative care have a need and a desire to share their stories and so enables

this work in a supportive and safe environment. Participants have the opportunity to learn from each other, are given time to reflect and reminisce on their life and in so doing make sense of their experiences. Participation in SS4WB can have positive outcomes for participants through encouraging a sense of autonomy and control. Through the process of reminiscence and telling one's story, participants can look beyond their patient identity and develop feelings of value and self-worth. SS4WB offers patients in palliative care opportunities to engage in a meaningful activity which can be enjoyable and socially engaging.

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