Exploring Audio Recording in Terminally Ill Patients Receiving Hospice Care “Stories for Life Charity” Model

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Abstract

Stories for Life is a UK charity that provides a free and confidential service for terminally ill patients to audio record their “life story.” Patients are given a copy of the recording and, if they wish, can then pass a copy on to their family/friends. This study explored how a group of terminally ill patients, receiving hospice care, experienced the process of making a voice recording of their biographies. Interviews were conducted with 5 terminally ill patients and 1 family member. Study participants found that talking to a trained volunteer provided a neutral, nonjudgmental interviewer. Patients reported a feeling of catharsis while telling their story as well as being able to reflect on significant life events. However, it was challenging to convey difficult emotions while also being mindful of protecting family who may listen to the recording. Although there was some uncertainty about how the recording would be perceived by listeners, leaving a voice-recorded life account was felt to be beneficial for immediate family members, as well as maintaining a meaningful connection with future generations. Overall, recording an audio biography in terminal illness can allow patients a space for reflection and a meaningful connection with their families.

Exploring audio recording in terminally ill patients receiving hospice care: 'Stories for Life Charity' model

Abstract

Introduction

Stories for Life is a UK charity that provides a free and confidential service for terminally ill patients to record their 'life story' on audio by trained volunteers, https://www.storiesforlife.co.uk/. Patients are given a copy of the recording, and if they wish, patients can then pass a copy on to their family members and friends. The psychological benefits of recording a life narrative in terminally ill patients are widely recognised. Examples include Harvey Chochinov's Dignity Therapy and Michiyo Ando's Short-Term Life Review.

Research question

How does a group of terminally-ill patients, receiving hospice care, experience the process of making a voice recording of their biographies?

Methods

Semi-structured in-depth interviews were conducted over Zoom with five terminally ill patients who had had an audio biography and one family member. Transcribed interviews were interpreted using thematic analysis.

Results

Study participants found that talking to a trained audio biographer provided a neutral, non-judgemental interviewer. The biographer helped them reminisce in a guided conversation navigating their life story in chronological order. Patients reported a feeling of catharsis while telling their story as well as being able to reflect and analyse significant life events. However, it was challenging to convey difficult emotions whilst also being mindful of protecting family/friends who will listen to the recording later. Although there was a degree of uncertainty about how the recording would be perceived by listeners, leaving a voice-recorded life account was felt to be beneficial for immediate family members, as well as maintaining a meaningful connection with future generations. Some individuals would have valued the opportunity to edit their recording and incorporate a visual component.

Conclusion

Recording an audio biography in terminal illness can allow patients a space for reflection and a meaningful connection with their families and future generations.

The study was approved by the London - Harrow Research Ethics Committee, reference number: 19/LO/1460.

Introduction

‘Stories for Life’ (FKA Hospice Biographers) is a charity that provides a free and confidential service for patients receiving end-of-life care, offering them the opportunity to ‘tell their story’ in a professionally recorded audio file.[1] Patients are given a digital copy of the recording which they can pass on to family and friends, providing a legacy for future generations. The charity has trained volunteers in over 60 hospices across the UK.

The benefits of recounting and sharing one’s life story has gained recognition and acceptance in academic and clinical circles alike. “The known advantages of doing such work,” writes Kunz of The International Institute for Reminiscence and Life Review include “finding meaning in life, improving problem-solving skills, assisting with the grief process, increasing emotional support, strengthening self-esteem [and] decreasing depression and anxiety.” [2]

Several models of using narrative in supporting terminally ill patients exist, including Dignity Therapy and Short-Term Life Review. [3, 4] Dignity Therapy asks patients to reflect on the value of their life and relationships with a trained healthcare professional. Sessions last between 30-60 minutes and patients’ stories are transcribed into a written account for families. [3] Patients reported an increased sense of purpose, reduced suffering and their families reported feeling consoled by the transcript.[5] Short-Term Life Review provides patients two sessions with a trained therapist to record a life review ‘album’ and to reflect together on the recording. [4] Results suggest Short-Term Life Review might improve the spiritual and psychosocial well-being of patients. [4] The body of research on narrative in terminal illness thus far suggests that therapeutic benefits are derived from both 1) telling one’s life story to somebody who will listen and 2) being able to share one’s story with family, friends, and caregivers. [6]

Stories for Life’s service

‘Stories for Life’ Charity offers terminally ill patients an audio recording after they have read an information sheet and agreed to accept the service. A trained biographer then contacts the patient to arrange a time and date for the recording. The biographer is a volunteer linked to the Hospice and has undertaken the Charity’s one-day training program on listening skills, rapport building, confidentiality and safeguarding. In a first preparatory meeting, the biographer asks the patient about the material they would like to cover, and the patient completes a consent form. The biographer then conducts the audio recording in person or via telephone. The biographer uses a chronological approach using the information already provided by the patient along with prompts if necessary. The recording can last anywhere between 5 minutes to an hour depending on the health and wishes of the patient. After the interview is complete, the patient receives the recording via a link on WeTransfer for the patient to download. The charity does not edit the recording in any way. Some patients undertake the recording over several sessions according to their health circumstances.

Rather than providing patients and their families with a written biographical document or transcript, ‘Stories for Life Charity’ facilitates a process whereby patients tell their stories verbally. The impact of both speaking and listening—for the person receiving hospice care and for the family/friend has not yet been formally studied.

The overall aim of this qualitative study is to describe the experience of a group of people either recording or listening to an audio biography. Our objectives were to: 1) explore how the process of recording an audio biography is experienced and valued by a group of people receiving hospice care, 2) understand how the process of telling a story orally and making a voice recording is different from other life story work from a terminally ill patient perspective and 3) appreciate the impact of listening to the recording on the person receiving the audio biography.

Methods

Study design

EHH and KA conducted five semi-structured in-depth interviews with terminally ill adults and one interview with a family member virtually over Zoom due to COVID-19 pandemic. Transcripts of the interviews were coded using thematic analysis. GC assisted with developing the study methodology and materials and RA with study methodology and data analysis. The study received funding from the University of Sussex (CHASE placement). The study was approved by the London - Harrow Research Ethics Committee, reference number: 19/LO/1460.

Recruitment

Inclusion criteria for the interviews were 1) patients receiving hospice care who had recorded an audio biography and 2) relatives/friends who received a copy of the recording. All study participants were adults over 18 years of age: three males (one > 45 years, and two > 65 years), and two females (one > 45, and one > 65) and one relative (female >65). A link person based at three hospices in England liaised with (EHH and KA) to help recruit patients and relatives. Posters were also displayed in these hospices inviting participants for interview. Eligible participants were then contacted directly or via the hospice link to arrange an interview date at their convenience with EHH and KA. Potential participants were then asked to take part in an interview by EHH and KA. Full information about the study, and a consent form (one for patient and one for relatives/carer) were sent via post or by email. It was made clear that non-participation would have no impact on the hospice care they receive. Five of the study participants were terminally ill with shortened life expectancy, hence EHH and KA were flexible to accommodate the interviews whenever convenient for participants.

Data collection

The interviews were semi-structured, using open ended questions to facilitate reflection and in-depth discussion (Appendix 1). Questions focused on the experience of preparing for and telling one's story during a recording session, participants' reflections and feelings, and expected and unexpected outcomes of telling one's story verbally. A topic guide for relatives aimed to unpick how hearing their loved one's voice, as well as their story, impacts on the relative's feelings and perceptions of imminent death of their relative. The interviews were audio recorded and transcribed verbatim. The transcripts were anonymised by removing all identifying information.

Data Analysis

Thematic analysis techniques were used to generate a description of themes across the data set. Analysis involved coding followed by identification and clustering of themes and production of a descriptive summary. Reliability was addressed by KA analysing a selection of transcripts, followed by discussion and consensus about themes with EHH. Finally, the themes were grouped and a narrative was constructed across the whole data set.

Results

The experience of recording an audio biography for patients

As previously outlined, the Charity offers a preparatory session for patients before the recording. Patients reported varying degrees of feeling prepared and not all had clear expectations about what recording a biography would entail. Whilst Patient 4 felt prepared stating that “they give us an idea of what we were going to say to them in regard to our lives”, Patient 3 did not feel sufficiently prepared and would have liked more time to freely talk and plan with the biographer about which areas of his life he wanted to talk about. He said, “I didn’t know whether and how much I would be guided in what to talk about… just to know some example questions perhaps would be good, yeah that would definitely help.” This patient felt he “wasn’t prepared” for some personal questions posed by the biographer about his family and past relationships before meeting his wife. He said he would have liked “a pre-interview interview to say…I don’t want to be asked about how I fell in love with that [ex-girlfriend].”

We also found that the amount of preparation undertaken by patients on their own varied. Patient 2 stated that she hadn’t prepared for the first session but that by the end of that session she felt she would have liked to have come with a clearer plan of what she was going to talk about, and to have come up with questions for the biographer to ask her. Patient 3 did a “mind-map” of their life in preparation. Patient 5 engaged in the recording with no planning at all and felt this was the right decision since “it might have diluted the process if I tried to really plan it… I think it ran a lot better and had more integrity by seeing what comes out rather than try and control everything.”

Some patients recorded their audio biography over multiple sessions (Patient 1 and 2) and others (patient 3) in just one session. Health and sensory limitations informed the duration and number of sessions. Patients who had more than one recording session were pleased with the time and space this afforded them, with patient 3 stated that he would have liked more than one session. Relative 1 stated that her father was very fatigued after the recording sessions.

Reflections on the biographer-patient relationship

Overall, patients found the trained biographer to be an interested but neutral, non-judgemental interviewer. Despite some initial apprehensions towards sharing their life stories with a volunteer, participants indicated that it was of beneficial to talk to a ‘stranger’. Patient 5 thought “it would have been lovely to have met [the biographer] and had a chat beforehand but I don’t think it took away anything”. Patient 2 ultimately appreciated the non-familiarity: “you talk about your life to a total stranger, which seems a bit weird but at the same time it kind of helps”. Patient 1 felt the biographer offered a listening ear not afforded by other relationships: “I would never be able to talk to [other people] about my life, because A: they are too young and B: they are not interested”. Patient 5 also emphasised the importance of telling someone his life story, and that person would “record the information sensitively and professionally”. Patient 2 suggested seeing the biographer on a video call rather than an audio call would have made her feel slightly more comfortable.

The biographer helped patients navigate their life story in a guided conversation in chronological order. Patients appreciated the opportunity to reflect on and analyse significant life events and found the biographer to facilitate their ability to remember and reminisce. As Patient 4 put it, “[the biographer] was somebody who jogs your memory…unless somebody asks us specific questions about your past you won't necessarily remember them”. Patients also liked the balance of direction and freedom the biographer provided in guiding the conversation—Patient 5 said the Biographer “was very good at just allowing me to go on that journey...it was fluid. It wasn’t too regimented.’

Patient 1 found that the recording instilled a sense of meaning and pride in her life: "I felt prouder than I did before of my life, before…I just had drab bits and pieces, but when you…hear it all together, you think 'my God, you really did have a good life didn't you', an interesting life". The word "cathartic" was also mentioned by both Patient 1 and Patient 5. Patient 3 acknowledged that he is a private person who does not like talking about his feelings; still he said he was "aware that not everyone is like me, and some people are just generally a bit more open…[still] I think it is definitely kind of great to have that recording".

Only one patient reported that the recording turned to the present time and the reality of her terminal illness. In that case, it was difficult to manage emotions. Upon discussing her cancer diagnosis, Patient 2 felt "this is the kind of emotions I was hoping that I would manage to take a hold of, but I had a bit of a cry during that time of the interview".

Patients' perceptions on the grieving process of family members who receive the recording.

Four of the five patients interviewed stated that being able to pass on their audio recording to relatives was a significant motivation for doing the recording. These patients felt the recording could act as an important legacy to pass to younger generations. The recording was a way of communicating one's life story to relatives providing an opportunity that would not ordinarily happen in day-to-day conversations. Patient 1 told us how "I want my granddaughter to be able to say 'this is my grandmother, this is the message she left me'…I tell them how much I love them and things like that but your life story is different". Patient 5 also felt that the recording provided an opportunity to tell his sons about his life in more detail. Patient 4 however was much less concerned with this legacy component, stating that he thought his wife might have a copy but that he may have deleted the content of the recording accidentally, but that "it doesn't really matter".

For Patient 2 and Patient 3, the main reason for doing the recording was for the benefit of their spouses and young children, as a way of maintaining a connection after their death and a way of being remembered. Patient 2 said that "I try to keep in mind that it is for the benefit of my daughter and my husband…so they can hear more things from me". This underlying reason affected what content was covered for Patient 3: "I didn't want to spend too long on the early stuff, especially considering it was very much for the children's' benefit."

It was challenging conveying difficult emotions and being mindful of how one's life stories might be perceived by family members. Patient 1 said ''I wanted it to be honest …but sometimes honesty could hurt and maybe I should have been more forgiving in some instances, but I think I have done the right thing in telling the truth." Despite Patient 4's initial indifference about sharing the recording with family members, he did express discomfort at talking about his difficult relationship with this father and how it "brings back unhappiness in the family and that's not what I want."

Patients 2, 3 and 5 shared a concern about the negative effects on family if they were to listen to the recording whilst they were still alive. As Patient 5 stated, "my intention was that I leave this recording for my wife and kids until after I passed so that they have got something. They have dealt with enough over the years, so it's better than shoving it in their face." For Patient 2 there was also a pressure to leave her young daughter with "positive stuff…I want her to remember me now as happy".

The significance of voice recording

Patients found the recording to be a faster and easier process when compared with writing an autobiographical play (Patient 1) or semi-autobiographical novel (Patient 4), neither of which were completed. Passing on a recording of one's voice was valued. Patient 2 said she felt "relief… there will still be something with my voice to give to". Patient 3 felt that "There is something lovely about hearing someone's voice". Nevertheless, 3 of the 5 patients said they would have valued the opportunity to incorporate a visual component. The ability of video recording to capture facial expressions and record how they looked before they became more ill was mentioned.

Two participants expressed the desire to edit the recording after they have listened to it. The reasons included wanting to edit out inarticulate sections and gaps in speech (Patient 1), and content about past relationships deemed inappropriate (Patient 2).

The recording was also a stimulant for doing other types of legacy work. Patient 1 described wanting to transcribe the recording to be a longer book-form narrative of her life to leave to her son.

A relative's reflection on the audio recording

Relative 1 was in the unique position of being present whilst her father's recording took place due to his dementia and needing further assistance. She felt the recording could not have taken place without her support: "I was able to kind of prompt him…so I was a very useful backup actually at times." It is not however customary for relatives to be involved in the recording process.

This participant found the presence of the biographer helpful in opening areas of conversation about her father's life: "it was delightful, having somebody else asking him questions… people talk to strangers…say things that never say to the family." The relative also felt the recording would be of value to her father's greatgrandchildren as a way of giving them insight into the historical period he lived in. However, she did not feel she learnt a lot of new information about her father and did not want to re-listen to the recording alongside her father whilst he was alive. Nevertheless, having a voice recording was appreciated for how it could capture the character of her father and its capacity to evoke memoires more readily than photographs.

On the perceived effects of the recording on her father, the participant felt "it has given him more opportunity to reminisce." However, she was aware of how tired her father was after the recording and how his memory impairment made recall a challenge.

Discussion

The objective of this study was to explore the experiences of patients who had recorded an audio biography and those of their relatives. Our study shows that 'Stories for Life' charity can provide patients with 1) a neutral, non-judgemental interviewer to guide recording a life story narrative and reminiscence and 2) a meaningful way to connect with their families and future generations. As the charity relies on trained volunteers rather than busy hospice staff, our study suggests that it is a service that could ease the pressure on stretched hospice services.

Our study found that the legacy component of the charity is integral to the experience of patients' recording. Whilst there is no obligation to share the recordings with others, our results demonstrate that patients were very aware of how audio recordings would be perceived by those who might listen to them. The legacy component creates an expectation of an audience, even if patients had no intention of passing it on (e.g. Patient 4). There is thus some tension between the task of a life review for personal insight versus that of a legacy. It is worth noting then that some patients may value the chance to record their life story with less emphasis on creating a legacy piece.

Our results show that for some younger patients, the benefits of recording an audio biography lay primarily in this legacy component, whilst older patients (65 years or older) appreciated the opportunity to reflect back on their life in addition to passing their life story onto their loved ones. The charity therefore has the task of accommodating what may be age-specific or individual preferences. The ability to tailor the recording to individual needs might be best attended to by ensuring sufficient preparation work goes on before the recording for example through an initial planning session, and perhaps a later revision or editing of the recording.

The experience of relative 1 was unusual in her involvement in assisting her father's recording. This set-up takes the recording further away from a space for individual reflection borne out of a one-to-one conversation with a trained biographer. But it does present a method for helping patients with certain conditions such as dementia in recording a collaborative biography recording that might benefit patients and relatives alike.

Ultimately, the purpose of the charity is facilitating the creation of an audio life narrative in chronological order. Because of the emphasis of documenting a life narrative in a biography, there was less space and opportunity for talking in depth about feelings in the present moment or exploring the experience of living with terminal illness. These feelings would be better addressed in other palliative interventions such as end-of-life psychotherapy.[7,8,9]

Chochnivov's Dignity Therapy provides patient's relatives with a transcribed document of the patient's recording.[1] Our results suggest that passing on an audio recording to loved ones benefits both patients and relatives and that the voice component is most valued. Incorporating a visual element and the opportunity to edit the recording may also be of value to some individuals.

Study limitations

Our study only included six participants. Four other potential participants were approached but declined to take part as they were no longer fit to be interviewed. We were only able to recruit one relative participant and so any conclusions relating to the impact of audio recording on relatives is limited. Due to the COVID pandemic, our study interviews that would ordinarily have taken place within a hospice setting were changed to virtual interviews. The patients whom we interviewed undertook their recording over the phone with the same biographer. Therefore, it is difficult to know about the experience of patients with different biographers and in-person recording. The charity has also expanded its services since we did the study interviews; patients can now be invited from acute hospitals and outpatient clinics as well as hospices. We also recognise that there are other models of life-review work that do not involve a legacy component.

Conclusions

This study provides a deeper understanding of the process and impact of voice recording, and the work of 'Stories for Life' charity for hospice patients and their family members and friends. We identified several therapeutic benefits of audio recording for patients relating to 1) personal insight via a condensed chronological life review and 2) legacy documentation for current and future generations. Overall, we found that the audio biography service can support the wellbeing of patients by reflecting on a life course journey. Whilst more research is required to confirm findings, this study provides preliminary evidence for the uniqueness of this charity in supporting patients, and their relatives.

References

1. Our ambition, vision and mission. Accessed December 30, 2022. https://www.storiesforlife.co.uk/our-ambition-vision-and-mission
2. Kunz, JA, Soltys FG. *Transformational Reminiscence: Life Story Work*. Springer Publishing; 2007.
3. Chochinov HM. Dignity-conserving care--a new model for palliative care: helping the patient feel valued. JAMA. 2002;287(17):2253-2260. doi:10.1001/jama.287.17.2253
4. Ando M, Morita T, Okamoto T, Ninosaka Y. One-week Short-Term Life Review interview can improve spiritual well-being of terminally ill cancer patients. Psychooncology. 2008;17(9):885-890. doi:10.1002/pon.1299
5. Montross-Thomas, Lori & Irwin, Scott & Meier, Emily & Gallegos, Jarred & Golshan, Shahrokh & Roeland, Eric & Mcneal, Helen & Munson, Diane & Rodseth, Laura. Enhancing legacy in palliative care: Study protocol for a randomized controlled trial of Dignity Therapy focused on positive outcomes. BMC palliative care. 2015;14. 44. 10.1186/s12904-015-0041-z.
6. Allen RS, Hilgeman MM, Ege MA, Shuster JL Jr, Burgio LD. Legacy activities as interventions approaching the end of life. J Palliat Med. 2008;11(7):1029-1038. doi:10.1089/jpm.2007.0294
7. Cohen ST, Block S. Issues in psychotherapy with terminally ill patients. Palliat Support Care. 2004;2(2):181-189. doi:10.1017/s1478951504040246
8. Breitbart W, Gibson C, Poppito SR, Berg A. Psychotherapeutic interventions at the end of life: a focus on meaning and spirituality. Can J Psychiatry. 2004;49(6):366-372. doi:10.1177/070674370404900605
9. Saracino RM, Rosenfeld B, Breitbart W, Chochinov HM. Psychotherapy at the End of Life. Am J Bioeth. 2019 Dec;19(12):19-28. doi: 10.1080/15265161.2019.1674552.

Appendix 1: Interview questions

Patient Questions:

Pre- recording

How did you come to record the biography?

Had you ever done anything like recording a biography before? Or telling stories about your life in written from?

What were you hoping to get out of recording a biography?

Describe your feelings before recording the biography? Were they mostly positive, negative, or a mix?

What impact did you think the recording would have on your wellbeing/your relatives/carers?

Did you feel sufficiently well informed about the recording process before the recording session?

Did you find it helpful to write down prior to the recording what you wanted to talk about on the Charity's pre-recording form?

During the recording

Can you tell me a bit about your experience of the recording and how you found it?

Did you go in with a clear idea of what you wanted to talk about? Did you stick to this or did what you talk about change in the course of the recording?

How did you feel as you spoke to the Biographer? How did you feel about them as a listener/interviewer?

What kind of emotions did you feel as you were recording the biography?

How did the actual experience of recording a biography compare to your expectations?

Post-recording

How did you feel/have felt since the recording took place?

Anything you wish you had said/not said in recording?

Are you glad that you recorded a biography? If yes, why? If no, why?

Would you recommend recording a biography to other hospice patients? If yes, why? If no, why?

Would you want to change anything about the whole process?

Have you given your USB sticks with the recording to anybody? If so, whom?

How did it feel to know this person/people have your biography recording?

Is it important to you that the biography is an audio recording rather than in written form? Or would you have preferred to express yourself in a different medium?

Relatives/Friends/Carer Questions:

What is your relationship to X?

How did you feel when you heard that X was having a biography recorded?

Did you know much about the charity or the process prior to the recording happening?

Have you listened to the recording? If not, why? If yes, tell me a bit about your experience listening to it.

How did you feel prior to listening to the recording?

How did you feel when you were listening to the recording?

How do you feel about being in possession of the recording? Do you think you will listen to it again/more times?

How do you feel about having X's voice/stories as an audio recording? How would you feel about having them in a different medium/format?

What do you think about the Charity's work of recording hospice patient's biographies? Would you change anything?