Original research

Palliative Care and Social Practice
2025, Vol. 19: 1–9
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DOI: 10.1177/26323524251375079
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Benefits and challenges of recording biographical audiobooks by incurably ill parents to their children: A semi-structured interview study

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Abstract

Background: There is initial evidence that biographical audio recordings have a positive effect on people with advanced, incurable illnesses, but also that such recordings can represent a major challenge. Little is yet known about the interactions of positive and negative effects, as well as certain groups of patients with incurable illnesses.

Objectives: The aim of this study is to identify positive and negative effects of a personal family audiobook recording on incurably ill patients with underage children, suggestions for improving the implementation, and feasibility in parallel with somatic treatment.

Design: Qualitative, descriptive study.

Methods: Semi-structured interviews, transcribed and analyzed using qualitative content analysis. The main categories were set deductively; the subcategories were developed inductively.

Results: Twelve patients with advanced, incurable diseases (66.67% female; age in years $M = 43.6$, range: 38–55) with children (<18 years) after recording a personal family audiobook. Patients experienced positive (e.g., relief, gratitude), negative (e.g., insecurity, sadness), and neutral emotions (e.g., feeling emotional, ambivalent). They described positive (e.g., pleasant memories) and negative effects for themselves (e.g., self-criticism), for their family (e.g., creating a legacy, no understanding, respectively), as well as positive and negative effects within the process of recording the audiobook (e.g., grateful for support, time investment, respectively). Some patients mentioned unspecific positive effects. The recording was easy to implement, as planning and implementation were individually adapted to the patients' needs. All patients would recommend the audiobook.

Conclusion: There was evidence that the audiobook strengthened coping strategies; the concept of generativity seems particularly important. Nevertheless, the process was described as exhausting and challenging. Therefore, patients should decide whether they want to record a family audiobook and should be in sufficiently good mental and physical condition when they start the recording.

Trial registration: German Clinical Trials Register (Deutsches Register Klinischer Studien; DRKS00029252); registration date: June 10, 2022.

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Plain language summary

Benefits and challenges of recording biographical audiobooks by incurably ill parents to their children: An interview study

Why was this study done? Previous research shows that biographical audio recordings have a positive effect on people with advanced, incurable illnesses; but also that such recordings can represent a major challenge. This study tries to identify positive and negative effects of a personal family audiobook recording on incurably ill patients with underage children, and suggestions for improving the process of recording an audiobook in parallel with somatic treatment.

What did the researchers do? Interviews were conducted with 12 patients with advanced, incurable diseases (66.67% female; average age in years $M = 43.6$) with children (age < 18 years) after recording a personal family audiobook.

What did the researchers find? Patients experience positive emotions (e.g. happiness, relief, gratitude, inspiration), cognitive and interpersonal outcomes (e.g. pleasant memories, creating a legacy, reviving, strengthening connections). They also report negative emotions (e.g. fear, disappointment, insecurity, sadness, exhaustion), cognitive and interpersonal outcomes (time constraints, little understanding from family members, self-criticism). However, all patients would recommend the audiobook. The recording was easy to implement, as planning and implementation were individually adapted to the patients' needs.

What do the findings mean? There was evidence that the audiobook strengthened coping strategies; leaving a legacy for their children seems particularly important. Nevertheless, the process was described as exhausting and challenging. Therefore, patients should decide whether they want to record a family audiobook and should be in sufficiently good mental and physical condition when they start the recording.

Keywords
palliative care, biography, audiobooks, parents, qualitative research, generativity

Received: 12 February 2025; accepted: 18 August 2025

Background

Biography work with and for patients with incurable illnesses started in the 1940s and was subsequently integrated into broader palliative care concepts as part of psychosocial and spiritual care, operationalized methodologically (e.g., as Dignity Therapy),[1] and more recently also investigated in controlled studies to validate its effects and effectiveness on existential suffering, anxiety, depressive symptoms, and further psychosocial distress.[2–5] A systematic review[2] showed that different biographical interventions had an effect regardless of the type and intensity. The different biographical approaches had a positive impact on quality of life as well as on spiritual well-being and reduced depressive symptoms. In addition to improving coping, biographical interventions offer the possibility of a legacy for loved ones.[6] A systematic review showed that most biographical interventions generate a written legacy.[7] A study on the intervention "life review interviews" showed that not all people benefit from this biography work; this was linked to the factors "worries about the future due to illness," "conflicts in family relationships," and "confrontation with practical problems."[8] A review summarizes that there has not yet been sufficient research on legacy in the social sciences.[9]

In recent years, initial projects in which audio recordings were used as part of biographical work have been scientifically evaluated. In the United States,[10] 20 palliative patients were interviewed about their life story at the end of their lives. Frequent topics of the recordings were family and relatives, life events, values, and the history of the illness. In the United Kingdom, two projects were researched in which terminally ill patients record their life stories.[11,12] The organizations "Stories for Life"[11] and "Oral History Society"[12] offer patients a voice recording of their biography supported by a trained volunteer. The patients benefited from neutral interviewers.[11] They perceived the recordings as validating and dignified,[12] reported a feeling of catharsis,[11] and felt a connection with themselves again outside of the patient role.[12] Family and friends emphasized the special nature of audio recordings as a memento.[12] However, it was perceived as challenging to deal with one's own difficult feelings on the one hand and at the same time to consider how the relatives would feel about the recordings.[11]

Legacy interventions are offered to a wide variety of patient groups.[13] A special patient group are parents with minor children. A systematic review shows that, depending on the age group, between 14% and 25% of cancer patients (curable and incurable) have minor children.[14]

Parents play an important role in preparing their children for their own death and supporting them through the process. Parents often need support for this difficult task.[15] In a study involving children who lost their parents before the age of 12, it was noted that some children would have liked to have audio or video recordings of their parents.[16] Since 2017, the family audiobook has been available to incurably ill parents with at least one child aged 17 or under. They can record professionally guided biographical audiobooks. One initial research project[17,18] showed evidence that biographical audiobook recording could have a moderating effect on patient distress. Nevertheless, research on auditory biography work for parents of minor children is still in its very beginning and further investigation is needed.[18] There are currently only very few studies on the topic and these often have a small sample size. Beyond that, there is little insight into the challenges of auditory biography work. For best practice, it is essential to know both the helpful and the disruptive factors. Therefore, the present study investigated the positive and negative effects of the recording of a family audiobook for incurable ill patients. Furthermore, we are interested in suggestions to improve the recording of a family audiobook as well as the feasibility next to somatic treatment.

Methods

We conducted semi-structured interviews with terminally ill cancer patients who recorded a family audiobook to explore benefits and challenges related to the recording. We were interested in the following research questions:

- How do patients experience the audiobook recording?
- Does the audiobook recording have positive and negative effects on the patients?
- Can the audiobook recording be included in the patients' daily routine and possibly their treatment plan?
- Are there wishes for improvement?

The Family Audiobook

The nonprofit project "The Family Audiobook" (www.familienhoerbuch.de) enables patients with an incurable illness and one or more underage children (age <18) to create a professionally supervised biographical audiobook. Focus is the parent's life story: Memories, experiences, and stories told by the parent. The recording of the audiobook is accompanied by specifically trained journalists who listen, ask questions if necessary, and make suggestions for the audiobook if required. The recordings can take place over several days at the patient's home, in a recording studio, or in rented premises; this is decided together with the patient. It is important that the patient can focus on the recording during this time; other people (e.g., family members) are not present during the recording. The recordings are edited by sound designers and compiled into a finished audiobook. Sound material (e.g., music) can be added. The audiobook is divided into chapters and lasts 6–7 h on average. The complete production of an audiobook takes about 100 working hours. The patients (and their families) receive the finished audiobook as digital document after the recording and post-processing, usually a few weeks after the recording. The audiobooks are donation-funded.

Study design

In this qualitative, descriptive study, patients were asked about their experiences after recording a family audiobook. The study is guided by the Consolidated Criteria for Reporting Qualitative Research (COREQ; Supplemental Material).

Setting

The interviews were led by study staff of the Heidelberg University Hospital, Germany. Due to the high burden of study participants and limitations due to the COVID-19 pandemic, interviews were conducted by telephone and audio recorded. S.E. (doctoral candidate, female) led all interviews after training by A.G. and took field notes. Interviews were led from November 2022 to August 2023.

Population and sample

The inclusion criteria were incurable illness (assessed by a physician from the study team or a psycho-oncologist from "The Family Audiobook"), being a parent of one or more underage children (<18 years), and being treated at the National Center for Tumor Diseases (NCT) Heidelberg or Heidelberg University Hospital or being a resident in the Rhine-Neckar region. All individuals who had recorded an audiobook and met the inclusion criteria were asked to take part in the interview.

Recruitment

Eligible patients were informed about the study by the hospital team of the Heidelberg University Hospital. In addition, flyers and posters were sent to the Heidelberg University Hospital, the NCT Heidelberg, oncology facilities, psychotherapists with a focus on cancer patients, and pastoral care providers. Also, staff members of "The Family Audiobook" promoted the study. Due to the broad advertising, it was not possible to survey how many patients the information reached. In an outpatient clinic of

Table 1. Semi-structured interview guideline.

Main questions	Follow-up questions
Topic 1: Experiences with the audiobook recording	
How did you experience your audiobook recording?	
How did you experience dealing so intensively with your illness but also with your life?	- Memories - Feelings
Topic 2: Coping, positive effects	
Did recording the audiobook have a positive effect on you?	- Before the recording? - During the recording? - After the recording? - Did anything change positively after the recording?
Did recording the audiobook have a positive effect on your family/relatives?	- Did the recording of the audiobook have a positive impact on your family?
Topic 3: Mental stress	
Did the recording of the audiobook have a negative, for example, unpleasant, or stressful effect?	- Before the recording? - During the recording? - After the recording? - Did anything change negatively after the recording?
Did the recording of the audiobook have a negative effect on your family/relatives?	- Did recording the audiobook change the way you interact with your family in a stressful way?
Topic 4: Practicability of the audiobook recording	
How did the audiobook recording fit into your daily routine, your life, and possibly your treatment plan?	- Did you feel like you found a good time to record? - What made it difficult to find a good time to record the audiobook?
Topic 5: Wishes and improvements	
If you had the opportunity to record an audiobook again, is there anything that you would want differently or change?	
Would you recommend the audiobook recording to others?	

The interview guideline consists of main questions (asked in every interview) and follow-up questions, which were asked if necessary.

the NCT, we approached 23 patients who met the inclusion criteria of whom eight recorded an audiobook (34.78%). Eligible, interested patients were contacted by study staff. They were informed about the study, signed consent forms, and then contact was established between the patient and "The Family Audiobook" association. All the patients who recorded an audiobook were asked to participate in a questionnaire survey and an interview after recording. The analysis was carried out in parallel with the conduction of the interviews. When no new categories were added during the analysis and the saturation of the content became apparent, recruitment was stopped.

Semi-structured interviews

The semi-structured interview guideline (Table 1) was developed after an in-depth literature review by a team of experts[19] – a palliative care physician (B.A.E., male), oncologists (L.B., male; B.A.E.), and psychological psychotherapists (A.G., female; B.D., female). B.A.E., B.D., and A.G. have experience in qualitative research. In the interview guidelines, five key topics are covered with the main questions followed by clarifying questions regarding the recording of the family audiobook: experiences, positive as well as negative effects, feasibility, and suggestions for improvement.

Qualitative data analysis

The interviews were transcribed verbatim (S.E.) according to predefined rules and analyzed by A.G. and S.E. with the help of qualitative content analysis after Mayring[20] using MAXQDA 2022.[21] The focus points of the interviews were set deductively, that is, theory-guided, and form the framework for the category system. The subcategories were developed inductively, that is, from the interview material.[20] Semantic units (words, sentences, or paragraphs) were labeled with codes and then grouped as more abstract (sub)categories. Only one code was assigned to each semantic unit. After the analysis of three interviews (25%), the category system was critically discussed by S.E. and A.G., adjusted, and the codes were reassigned. The process of coding and categorization was continuously discussed by the research team until we reached consensus and data saturation. We applied descriptive quantitative methods (frequency distribution, mean scores, and standard deviation) to evaluate the sociodemographic variables.

Results

Sample description

Twenty patients with incurable cancer were enrolled of whom eight were excluded: Five individuals died before

Table 2. Overview of the category system.

Categories and subcategories	n_{codes}	$n_{\text{participants}}$
Emotions in the context of audiobook recording	199	12
Positive	71	12
Negative	94	12
Neutral	34	10
Positive effects	179	12
Personal effects	63	12
Social environment/family	42	11
Audiobook execution	68	12
Unspecific positive effects	6	5
Negative effects	43	7
Personal effects	6	5
Social environment/family	15	5
Audiobook execution	22	5
Feasibility of audiobook recording	43	12
Planning audiobook recording	6	4
Recording process	29	12
Impact on somatic therapy	8	5
Wishes and suggestions for improvement	34	12
Recommendation of audiobook recording	15	12
Recording process	11	7
General wishes	8	6

n_{codes}: number of codes; $n_{\text{participants}}$: number of participants.

the interview date, two persons did not respond to scheduling the interview, and one patient decided to withdraw from the study after inclusion. In total, interviews were conducted with 12 patients, 8 of whom were female (66.67%). The participants were between 38 and 55 years old, with an average age of 43.58 years. They had between one and three children ($M = 1.75$). The number of minor children ranged from 1 to 3 ($M = 1.58$). All the patients had a cancer diagnosis. The average length of the recorded interviews is 15.73 min.

Qualitative content analysis

The qualitative analysis of the interviews revealed 498 single codes, which were grouped into five main categories (Table 2). The categories are outlined below with sample quotations. The quotes are followed by the codes of the study participants in parentheses.

Emotions in the context of the audiobook recording

All the participants named positive emotions. They were happy about the opportunity to record, enjoyed the recording itself, and were looking forward to the result. In addition, the recordings were perceived as psychological relief: "*Yes, a bit of relief that I did it; that I was able to do it*" (G). Also, the knowledge that their child(ren) would learn something about them by listening to the audiobook was felt as a relief. It was perceived as liberation to speak out about certain topics. At the end, the participants felt that they had accomplished something valuable. Some participants were filled with gratitude: "*. . .that I am actually very, very grateful that something like this is offered for families at all*" (F). They felt noticed and heard, and mental strength was drawn from the audiobook recording: "*And I personally have the feeling that it has given us [the family], well me anyway, a lot of strength*" (D). The recordings were perceived as exciting and inspiring experiences that triggered satisfaction and pride.

The participants also named negative emotions. Before the recording, a few patients were afraid of what was about to come when recording their audiobooks. One patient was disappointed about the organization prior to admission. Many felt insecure, both in terms of the recording situation and the content of what they wanted to tell: "*At the beginning I thought*, '*Oh God, everyone must be talking about their great trips and all the great things they have experienced, and I have not done that at all. I have never done such big trips*'" (D). The recordings also caused a lot of sadness, especially when it came to their illness: "*But then at some point it's also the case that I'm no longer there and then [they] have to listen to it on [their] own, and that's a bit sad, it made me sad*" (G). Many participants found the confrontation with their own biography agitating and stressful: "*There were some chapters that were harder to tell*" (E). They found the recording process itself physically exhausting: "*So, I really lost my voice on the last third day (laughter) [. . .]. So that was quite a challenge for my vocal chords (laughter).*" (F) and emotionally challenging: "*. . .when she asked about the relationships with the children (. . .) this chapter with the children was very difficult for me, because they are still small – they are not that small anymore – but they are still children and are too young and don't really understand that yet . . .*" (A).

Memories that surfaced during the recording were described as emotional but not explained in more detail: "*Therefore, it was truly everything in between, it was all there. However, yes. Exactly, just like life is*" (G). Some had ambivalent feelings. A few participants reported that the recording had made no difference emotionally: "*I don't think I know whether the three days of recording made me feel any different afterwards than I did the day before*" (E). This was partly related to the fact that their own illness was not (yet) perceived as very frightening or threatening: "*To be fair, I have to say that I'm seriously ill, I have a very serious illness, but I don't feel it yet. So, I'm doing relatively well, I'm on medication. I'm not in any pain now and I'm not suffering so much physically from the illness*" (A). Some participants had also done other things before to create legacies for their children, for example, creating a book.

Positive effects

The most frequently named personal impact was memories. The participants remembered many pleasant moments; many memories had resurfaced. Furthermore, the recordings raised awareness that the participants were able to look back on a beautiful life. The recordings gave the feeling of having a new project in life: "*You might also have an idea of what you could do or arrange in the remaining time. Especially in connection with my daughter. What else should be done. The next question, of course, is whether it will work*" (E). For some people, the illness tended to fade into the background because it was no longer the only focus.

Positive effects on the social environment, especially in the family, were also perceived. Especially important was the feeling of being able to leave something very personal, something that would outlive one's own death: "*Because I can actually say that I have left my children an enormous treasure, in my eyes, and I think they will see it that way too. They have something tangible, they have my voice*" (G). In addition, it was described that the recording intensified the contacts in the here and now. The participants contacted old friends or noticed that the audiobook was a topic of conversation. Connections in the core family were strengthened. One participant said: ". . .*talked to my parents and reactivated old contacts with friends. And that is one thing that is really nice, because old friendships that had been forgotten have been revived*" (D).

The overall recording process was described as positive; some participants felt more comfortable over the course of the three recording days. The participants were grateful for the support and guidance of an audiobiographer: ". . . *the autobiographer also organized it with me the whole time without any pressure. I thought that was very good. She said, 'We will plan it now in the three days and if it does not work, then it does not work, then we will find another solution'. She fully adjusted to my needs*" (D). The participants liked to look at old photos and videos. Positive family support was important for both concrete actions and attitudes.

Some participants described positive effects from recording the audiobook without specifying them, for example, "*It is not so much the recording of the audiobook as the idea of the audiobook in the first place and the fact of doing it. I think that has a positive influence*" (E).

Negative effects

Negative effects were described, most frequently related to the recording. The recording appointments had to be planned and prepared. The time used for creating the audiobook was lacking elsewhere (e.g., childcare). Some patients were annoyed afterwards when they thought of something they wanted to be included in the audiobook but did not mention it during the recordings: "*Above all, I always thought of something afterwards that I would have liked to say (laughter)*" (E).

There were also negative effects on the family. The relatives did not always react with understanding to the wish of the audiobook recording. On several occasions, the recordings brought the severity of the illness to the awareness of the family: "*My mother said that I had recorded the audiobook and she was a bit perplexed, like 'why would I have done that? I will never need that'. . .*" (I).

Individual participants spoke about negative effects on themselves. Some were too self-critical during the recording, while others found it uncomfortable to talk about such personal topics in front of a stranger:

> ". . . *perhaps not having experienced so much or not having experienced such great things that you can now pass on to the children*" (L).
>
> "*So, it is definitely the case when you have to talk about things like that in front of someone you do not know, and that is because you do not know the audiobiographer, that somehow does something to you, of course*" (B).

Feasibility of the audiobook recordings

Participants were asked about the feasibility of implementing the audiobooks. They referred to the recording process, planning, and effects on somatic treatment. The recording process was about pragmatic points such as freeing up time but also about whether a good time was chosen for the recording. A few times, it was perceived as an advantage to have a longer time between the initial diagnosis and the audiobook recording. The participants were satisfied with the execution of their audiobooks. Most participants did not feel that the audiobook recording interfered with somatic treatment: "*Yes, so my treatment continues almost completely independently of the audiobook according to the treatment plan*" (I). However, planning the audiobook recording took time. It was not always easy to find a common date with the audiobiographer; childcare had to be arranged, and the participants had to be in sufficiently good health:

> "*I usually look after my children in the afternoons. That had to be planned and organized a bit*" (D).
>
> "*I told my oncologist and he immediately gave me the okay to have a break, so I have to have chemotherapy every 14 days. And then we took an extra week off so that I would have the strength and energy for it*" (D).

Wishes and suggestions for improvement

All the participants would recommend the Family Audiobook to others. Some would recommend it to everyone – even those who are not terminally ill: "*I mean, I now have four parents, so to speak, two parents and two parents-in-law. Maybe it would also make sense to make an audiobook for them. Because losing parents is bad, but losing your own children, even if they're already grown up, I think that is bad too*" (E); while others would consider it well to whom they recommend it: "*Well, it depends on who I would tell (laughter). Well, I would not tell everyone, but all in all, yes*" (A). General wishes were also named: Some participants would prepare more intensively for the recordings in retrospect: "*Then I would have had to be at home in between, record a day and then have a day off for preparation (. . .). But then I would have had to be at home for that one day with all the documents (. . .), where I could have looked something up again*." (E). Some would have liked closer grief counseling. Others, however, were also satisfied without any more wishes.

Discussion

Main findings

In this study, the feasibility and the positive and negative effects of recording a biographical audiobook in patients suffering from an incurable illness with child(ren) aged 17 or younger were examined.

The included patients – middle-aged adults with incurable cancer and underage child(ren) – represent a particularly vulnerable group. In addition to worrying about their own illness, they also have to worry about their children, who lose a parent at an early age.[22] More women (66.67%) than men took part in the interviews. This is in line with previous studies, which have shown that White middle-class females in particular seek social support when suffering from cancer.[23] The dropout rate of 40% is also in line with the previous literature. Patients in a palliative setting are motivated to participate in studies.[24] However, the progression of the disease and thus the deterioration of the state of health can prevent actual participation. Adapting the audiobook recording (location, length of appointments, breaks, coordination with somatic treatment) to the individual situation of the participants is unavoidable and a known factor for the feasibility of such interventions.[25] The burden of the patient group could explain the relatively short interview duration of 16 min on average.

Patients reported increased personal resources (e.g., satisfaction, pride, and psychological relief) and increased social resources, including support and family cohesion. Positive effects were the creation of a legacy for the children, a distraction through the audiobook recording, and the creation of awareness in various areas, for example, regarding one's own past life. The recording itself, especially the collaboration with the autobiographers, was perceived as positive. In contrast, the audiobook intervention was also associated with negative emotions such as distress, uncertainty, and sadness. Negative effects were also evident among family members if they first or again became aware of the palliative illness and its consequences through the audiobook recording. The time required and the worry of forgetting something important during the recording were mentioned. The planning and implementation of the audiobook recordings were individually adapted to the needs of the patients so that the recording could be easily integrated into the patients' therapy plan. Overall, patients named more positive feelings and effects related to the audiobook than negative ones. Furthermore, all patients would recommend the audiobook recording. These findings are in line with previous research.[11,12]

What this study adds

Compared to other biographical interventions, family audiobooks are time-consuming; up to three full days are planned for the recording. Many patients described that they prepared themselves before the recording and then looked for additional materials (such as songs). For example, as part of dignity therapy, 1- to 2-h interviews are being conducted usually without any preparation of the patients.[26] The significantly greater effort required might represent greater hindrance for patients. This was reflected in our study in a rather low participation rate. In particular, in the period immediately before death, parents reported in another study that they wanted to spend the remaining time with their loved ones undisturbed.[27]

The accompaniment provided by the audiobiographers was often named a positive aspect of the audiobook recording. This is in line with one other study about biographical audio recordings in terminally ill patients.[11] This fits in with the wish of dying parents for support in how they can best accompany their children through the process.[15] It also can be explained with containment[28]: The audiobiographer received affects, processed them, and reciprocated them in a sympathetic way. This was done by listening attentively and responding to the feelings understood. This helped patients recognize, acknowledge, and process their own feelings. The study participants reported a benevolent and trusting attitude on the part of the audiobiographers, which is a precondition for containing.

Creating an audiobook can be seen as a form of generativity[29]; the feeling of leaving a legacy for future generations, for example, in the form of caring or guidance. Many study participants described their desire to be able to pass on some of their experiences and knowledge to their children. This helps to preserve memories with and about the deceased parent. The audiobook format helps to "capture the [. . .] voice of the deceased parent."[16] In other studies, relatives and close friends also emphasized the special nature of an auditory memory.[12] In addition, research shows that biographical narratives can help to create meaning and a continuity of the self. Both topics play a particularly important role for palliative patients.[6,30] Finding meaning in life is, in turn, closely linked to generativity.[31]

The results of our study can be discussed well in the context of coping concepts.[32] First, recording an audiobook represents an immense confrontation with the incurable disease, so that only people who are not averse to dealing with it explicitly (coping mechanism) will record an audiobook. Some relatives, however, found it difficult to come to terms with the audiobook recording, as it made them (again) aware of the incurability of the illness. Second, even though negative feelings were repeatedly mentioned, positive aspects such as inspiration, pride, and satisfaction seemed to be more pronounced across the interviews. Third, for the participants, it was a relief to know that their voice and the stories told would remain with their children. Patients can do something themselves to make their illness slightly more bearable (self-efficacy). Dying parents can choose for themselves what they want to tell their children in the audiobooks, thereby influencing the culture of remembrance.[16,27]

Recording the audiobook automatically leads to an awareness of one's own biography. This may lead to negative emotions, but can be of benefit in further confrontation with the disease. Especially at an advanced stage of the disease and at a young age, the confrontation with one's own illness is often not successful without taking one's personal life story into account.[22]

Limitations of the study

The present study is exploratory with a small sample size. Nevertheless, the interviews provide important insights into the patients' experiences of recording a family audiobook. Only patients with a cancer diagnosis participated; further research is needed to see if other patient groups report similar experiences. Selection bias cannot be ruled out, as the participants presumably hoped for something positive from the audiobook recording from the very beginning. However, even outside of research, people will only record an audiobook if they have a positive attitude toward it.

Conclusion

In summary, the participants interviewed drew more positive than negative conclusions from the audiobook recordings. The concept of generativity seems important. There were indicators that the audiobook strengthened coping skills. Nevertheless, the process was also described as demanding and challenging; therefore, patients should be free to choose whether they want to record a family audiobook. Furthermore, they should be in a sufficiently good physical condition when starting the recording.

Acknowledgements

We would like to thank all the employees of the family audiobook, especially Judith Grümmer, Sabine Fiedler, Petra Steinbach, and Elisabeth Szwarc. This study was financially supported by the National Center for Tumor Diseases (NCT) in Heidelberg, Germany, and the Dietmar-Hopp Stiftung. The publication of this article was funded by the University of Mannheim.

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Ethical considerations

This study was approved by the Ethics Committee of the Heidelberg Medical Faculty (S-345/2022). This study was conducted in accordance with the Declaration of Helsinki (most recent version; Fortaleza, Brazil, 2013) and registered with the German Clinical Trials Register (Deutsches Register Klinischer Studien; DRKS00029252).

Consent to participate

All the participants provided written informed consent to participate and were able to withdraw their participation without any disadvantage.

Author contributions

Anja Greinacher: Data curation; Formal analysis; Methodology; Project administration; Writing – original draft.
Sophia Enders: Data curation; Formal analysis; Project administration; Writing – original draft.
Lars Buschhorn: Conceptualization; Funding acquisition; Writing – review & editing.
Beate Ditzen: Conceptualization; Writing – review & editing.
Bernd Alt-Epping: Conceptualization; Funding acquisition; Writing – review & editing.

Funding

The authors disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: The study was supported by the National Center for Tumor Diseases (NCT) Heidelberg, in Heidelberg, Germany, and the Dietmar-Hopp Stiftung.

Declaration of conflicting interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Data availability statement

The data cannot be shared publicly because the interview transcripts contain personal data, including information that may allow personal identification of participants.

Supplemental material

Supplemental material for this article is available online.

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