



A low literacy targeted talking book about radiation therapy for cancer: development and acceptability

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Abstract

Purpose To develop a low literacy talking book (written book with accompanying audio-recording) about radiation therapy and explore its acceptability with patients and caregivers.

Method The talking book was developed iteratively using low literacy design principles and a multidisciplinary committee comprising consumers and experts in radiation oncology, nursing, behavioural sciences, and linguistics. It contained illustrations, photos, and information on: treatment planning, daily treatment, side effects, psychosocial health, and a glossary of medical terms. Semi-structured interviews were conducted with patients who self-reported low functional health literacy and caregivers to explore their views on the resource. Thematic analysis using a framework approach informed the analysis.

Results Participants were very satisfied with the content, illustrations, and language in the resource. Most were unfamiliar with the term ‘talking book’, but liked the option of different media (text and audio). The resource was seen as facilitating communication with the cancer care team by prompting question-asking and equipping patients and their families with knowledge to communicate confidently.

Conclusions The low literacy talking book was well accepted by patients and their caregivers. The next step is to examine the effect of the resource on patients’ knowledge, anxiety, concerns, and communication with the cancer care team.

Keywords Radiation therapy · Cancer · Communication · Knowledge · Health literacy · Talking book · Qualitative

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Introduction

Radiation therapy is a widely used treatment for various types of cancer. Guidelines recommend approximately 50% of patients with cancer should receive radiation therapy to improve their quality of life and reduce mortality [1]. Patients' understanding of radiation therapy has been shown to be limited, and they report feeling uncertain about what to expect before, during and after treatment [2]. Our previous research showed patients seem particularly unclear about treatment planning, the efficacy of radiation therapy, how the treatment machines work, the management and intensity of side-effects, and the frequency and nature of follow-up visits [3]. Approximately, 50% of patients experience anxiety during their planning appointments before they start treatment [4]. Efforts are needed to better prepare patients prior to commencing treatment to help improve psychological outcomes and quality of life [5, 6].

In Australia, there is considerable variability in radiation oncology departments with regard to who is responsible for delivering information, and when it is delivered. As a result, information can be contradictory and poorly timed [7]. Patients often struggle to recall information after consultations [8], and medical jargon may be used without clarification [9]. It is important that patients have access to clear and easy-to-understand information that they can take home and read.

Take-home resources play a critical role in complementing and reinforcing verbal information, enabling patients to process and share information in their own time. When developing such resources, it is important to be mindful of the health literacy skills of the target group to ensure information can be accessed, understood, and used on an equitable basis [10, 11]. Low health literacy is common [12] and is associated with an increased risk of morbidity and mortality and poorer physical health [13, 14]. Individuals with low health literacy are less likely to experience patient-centred communication and have greater difficulties managing chronic conditions [15]. To our knowledge, no patient education resources have been specifically developed for lower health literacy populations in the context of radiation oncology [16].

The current study sought to develop a low literacy, psycho-educational talking book (written book with accompanying audio-recording) designed to increase knowledge about radiation therapy, reduce anxiety, and facilitate communication between patients, caregivers, and the cancer care team. The talking book was designed to be used by patients, caregivers, and healthcare professionals prior to treatment planning, a time when information needs and anxiety are often heightened [17]. Talking books have been shown to increase reading fluency and comprehension among people living in rural and remote communities in developing countries [18–20]. Recent work by Goeman et al. found a bi-lingual, online Vietnamese talking book about dementia to help older adults

and their families gain a better understanding of memory loss and how to access support and services in the community.

The aims of the study were to (1) develop a low literacy talking book about radiation therapy and (2) explore the acceptability and comprehensibility of the talking book among patients with low functional health literacy and caregivers. Qualitative, semi-structured interviews were performed with patients who were nearing completion of radiation therapy. This enabled us to retrospectively explore what information would have been helpful to them as they commenced treatment.

Methods

There were three stages to the project (Fig. 1). This paper reports stage 1.

Stage 1a: development of the radiation therapy talking book using an iterative design process

A multidisciplinary team (comprising cancer consumer representatives, researchers, and healthcare professionals with expertise in radiation therapy, nursing, behavioural science, psychology, health literacy, and linguistics) developed the first draft of the A4-size talking book.

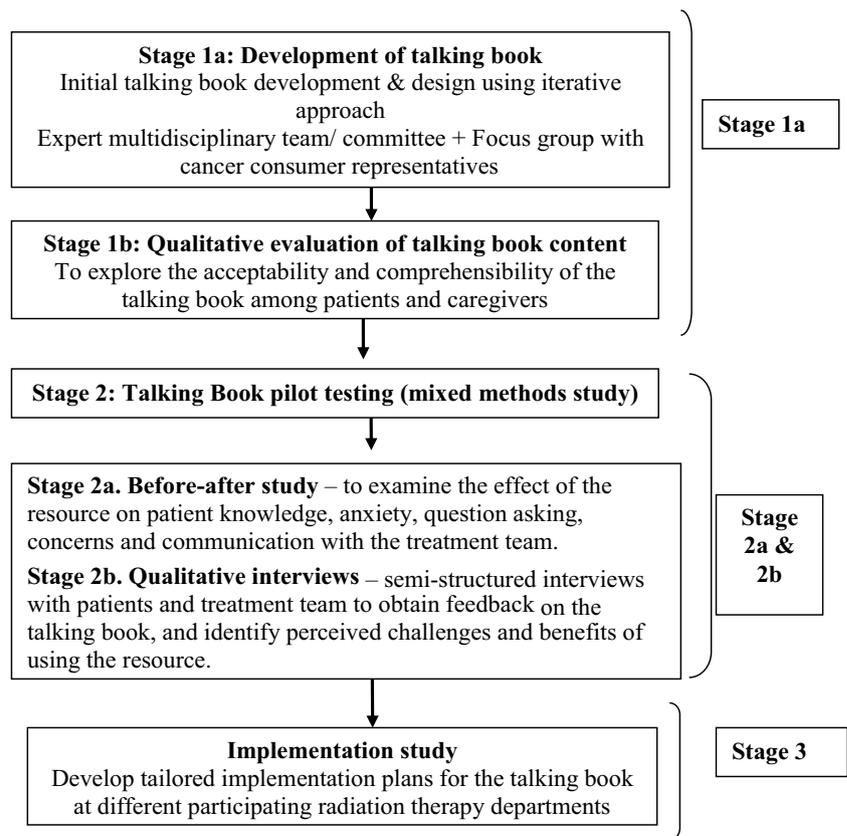
The content and design of the resource drew upon our previous work ([2, 22–24], existing resources [16]), and professional guidelines. Low literacy design principles were applied (e.g. non-technical language, colour coding, glossary of medical terms, illustrations, photos, medical diagrams) [11, 25–27].

The resource contains sensory and procedural information to inform patients about what they are likely to experience (feel, hear, and see) and what will happen before, during, and after treatment [28] (Table 1). We created two sample audio voice recordings (male and female voice) to elicit preferences for each voice.

The authors developed an initial draft and obtained individual feedback from radiation oncologists, radiation therapists, radiation oncology nurses, and cancer consumer representatives. A face-to-face workshop with the multidisciplinary team took place, and the volume of content was reduced to ensure coverage of key messages without overwhelming users.

A focus group comprising ten cancer consumer representatives was conducted to elicit feedback on the resource. All focus group participants had been personally affected by cancer as a patient or caregiver and were members of the Translational Cancer Research Network's Consumer Advisory Committee—a translational and collaborative cancer research network in Sydney, New South Wales. Participants felt the talking book represented a balanced view and created realistic expectations of treatment. However, participants highlighted that although

Fig. 1 Flow chart of the Talking Book development, pilot testing and implementation phases



the language was clear, it was perceived as impersonal. Participants also reported a range of perceptions about the purpose of the resource perceiving it as designed to increase the uptake of treatment, as opposed to knowledge. Amendments to the talking book were made to address participants' concerns.

Stage 1(b): qualitative evaluation of talking book content with patients and caregivers

A qualitative approach using semi-structured interviews was used to obtain feedback on the talking book content with patients and caregivers.

Participant recruitment and procedure

Qualitative interviews were conducted from March to July 2015 with patients and caregivers to explore the acceptability and usefulness of the talking book. Ethical approval was granted by the South Eastern Sydney Local Health District Human Research Ethics Committee.

Patients

Patients were eligible for the study if they had been diagnosed with any type and stage of cancer, for which they were receiving external beam radiation therapy, were aged 18 years of age

and over, were able to read and understand English, and have self-reported low functional health literacy skills. Patients were not eligible if they were too unwell or had serious cognitive or psychiatric impairments.

Patients were informed about the study by their radiation oncologist. Those who expressed an interest were given a participant information sheet and telephoned by the research officer who provided more information and assessed their functional health literacy using questions shown to be effective in detecting inadequate health literacy: (1) How confident are you filling out medical forms by yourself? (five possible responses from extremely to not at all), (2) How often do you have someone help you read hospital materials?, and (3) How often do you have problems learning about your medical condition because of difficulty in understanding written information? The five response options for both of these items ranged from always to never [29]. Participants were classified as having lower functional health literacy if they responded with 'Somewhat' or 'A little bit' or 'Not at all' to question 1, and 'Always' or 'Often' or 'Sometimes' to questions 2 and 3.

If eligible and verbal consent was obtained, an interview time was arranged, and participants were posted a copy of the talking book and sample voice recordings. The interview schedule explored participants' experiences of receiving information, feedback on the content, design and clarity of the talking book, how they would use the talking book, and suggestions for its improvement (see Supplementary file 1).

Table 1 Topics presented in the talking book

Topic	Brief description of content
What is cancer?	Describes the difference between malignant and benign tumours; presents an image of a malignant tumour (cancer cells dividing and a tumour forming)
Types of treatment	Describes the different types of cancer treatment—surgery, radiation therapy (external (external beam) and internal (brachytherapy)), chemotherapy, immunotherapy, and hormone therapy. Explains that the booklet focuses on external beam radiation therapy.
Your cancer care team	Presents a table listing the various health professionals comprising the cancer care team and their role in cancer care—GP, radiation oncologist, registrar, radiation therapist, radiation oncology nurse, dietician, speech pathologist, psychologist, physiotherapist, and social worker.
What is radiation therapy?	Describes what radiation therapy is (special type of X-rays (high energy) to kill or damage cancer cells) and explains the duration of radiation therapy and why radiation therapy is used—to cure, control, relieve symptoms and help other cancer treatments to be more effective.
Treatment planning	Explains how planning the radiation therapy treatment involves 3 key steps, and describes each step in detail—appointment with the radiation oncologist, designing the radiation therapy treatment plan, and treatment planning appointment. No treatment at this point. Includes photos and illustrations of a patient having a CT scan, radiation therapist tattooing a patient's skin, a patient lying on a body mould and a patient wearing a face mask.
Having treatment	Explains how treatment involves 3 steps, and describes each in detail—before treatment starts, during treatment sessions, and after each treatment session. Includes illustrations of a radiation therapist operating treatment machines.
What happens after treatment	Explains what happens once treatment finishes—frequency of follow-up visits
Side effects and emotions	Explains in detail about the potential side effects that might be experienced with treatment and suggestions to cope with them—fatigue, skin problems/changes, loss of appetite, diarrhoea, hair problems, nausea, mouth problems, effect on sex life. Explains the different emotions that might be experienced and suggestions how to cope with them.
Support and contacts	Provides contact details of the various cancer organisations and information on parking and accommodation.
Questions to ask the cancer care team	A list of questions to ask the cancer care team about treatment, preparing for treatment, side effects, the cancer care team, costs, and transport/accommodation services.
Medical words	A glossary of the medical terms/phrases used in the book

Caregivers

Caregivers were invited to take part by the radiation oncologist if they met the eligibility criteria: 18 years and over, supporting a person aged 18 years or older undergoing external beam radiation therapy, and able to read and understand English. Caregivers were able to participate if the patient they were supporting was not eligible, or did not want to participate. If eligible and verbal consent was obtained, the talking book and sample voice recordings were posted, and a suitable interview date and time was arranged to obtain their feedback on the resource using the interview schedule (Supplementary file 1).

Analysis

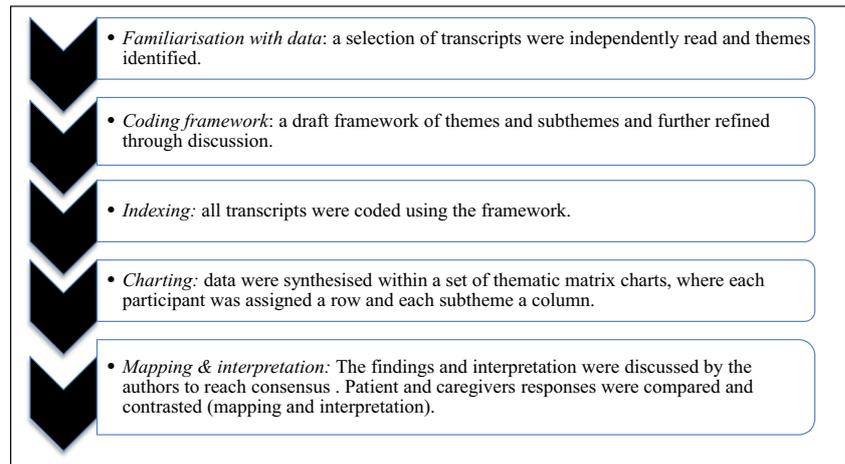
All interviews were audio-recorded and transcribed verbatim. The analysis was carried out by authors, using Framework approach, a thematic analysis method involving five stages (Fig. 2) [30].

Results

Participant characteristics

Sixteen patients and ten caregivers completed the interviews (Tables 2 respectively). Patients were mostly female ($n = 13$),

Fig. 2 Stages of Framework analysis



with a mean age of 61 years. All participants were receiving treatment for different cancer diagnoses. Six of the ten caregivers were male, mean age 63 years. Most were married ($n = 9$) and caring for their partner ($n = 8$).

On average, interviews lasted for 24 min (range 12–46 min). Twenty of the interviews were carried out over the telephone, and six were face-to-face.

Themes

Overall, there was broad similarity in patient and caregiver responses; consequently, the themes described below reflect both groups. Where present, we describe differences between the two groups. The following key themes were identified and presented below with illustrative quotes: (1) reactions to the concept of a talking book; (2) appraisal of the talking book content, language, and structure; (3) when to use the talking book; and (4) perceived challenges and benefits of using the talking book with the cancer care team and others.

Reactions to the concept of a talking book

There were mixed responses from participants about the notion of a talking book format. This was partly due to a lack of familiarity with the concept. Some participants suggested the term ‘talking book’ was misleading as it suggested the book talked to the reader automatically as the pages are turned. Several patients and caregivers suggested it would be better described as a ‘booklet with an audio guide’ to clarify the book was accompanied by a USB or CD providing the audio content.

I think it’s a wrong name, talking book. Because the book can’t talk. (patient no. 9, female, age 47, breast cancer)

It’s not really a talking book, it’s a guide for patients and their families to radiotherapy and you’re giving someone a CD (caregiver no. 8, male, age 70, caring for his wife)

Some caregivers expressed concern that older patients may not have the technology or computer literacy skills to listen to the book. These people indicated they would play the recording when driving the patient to the hospital.

My mum would need to read the book because she is not computer literate to do that (caregiver no. 12, female, age 42, caring for mother)

Despite these concerns, most participants could see the value in the option to read and/or listen to the information while doing other things. They felt the format would be helpful for people with reading difficulties, and those who did not speak or read English as a first language.

A talking book allows you to relax and just listen at times when you might not be able to give your full attention to holding a book and reading (caregiver no. 4, male, age 58, caring for wife)

There are a lot of immigrants in Australia and to listen to the recording and read at the same time, they will get a better understanding (patient no. 63, female, age 61, breast cancer)

Overall, most participants expressed a preference for the female rather than the male voice recording as it sounded more professional, softer, and clearer. Some participants thought the female voice might be more appropriate for women undergoing breast cancer treatment as her tone expressed more compassion and understanding.

Table 2 Patient ($n = 16$) and caregiver ($n = 10$) demographics

Demographic variable and categories	Patients ($n = 16$)	Caregivers ¹¹ ($n = 10$)
Age years, mean (range, SD)	61 (33–74, 11.5)	63 (43–84, 14.1)
Gender		
Female	13	4
Male	3	6
Marital status		
Single	1	0
Widowed	1	0
Married	7	9
Divorced/separated	7	1
Highest level of education completed		
High school (year 10 or below)	6	0
Year 12 (higher school certificate)	1	4
TAFE diploma/certificate	3	3
University degree	6	3
Occupation (current or previous, if retired)		
Professional	6	4
Labourer/trade	3	1
Clerical/sales	7	5
Current employment status		
Retired	6	5
In paid employment	5	5
Home-maker	3	0
Unemployed	2	0
Main language spoken at home		
English	14	9
Other	2	1
Country of birth		
Australia	12	9
Other	4	1
Type of cancer		
Breast	7	2
Skin	3	3
Brain	2	0
Colorectal	2	0
Gynaecological	1	1
Lung	1	2
Prostate	0	1
Oral	0	1
Previous cancer treatment received*		
Surgery	15	N/A
Chemotherapy	10	
Radiation therapy	6	
Endocrine therapy	3	
Support person attending consultations		
Yes	4	
No		
Support person—relationship to patient		N/A
Spouse	6	
Child	3	
Sibling	1	
Other relative	1	
Friend	1	
Caregiver relationship to patient	N/A	
Spouse-partner		8
Child		2

*Caregivers were able to participate if the patient they were supporting was not eligible, or did not want to participate

I do prefer the female, it's just because being female and breast cancer is related, so I related to the female more rather than the male (patient no. 23, female, age 66, breast cancer)

Appraisal of the talking book content, language, and structure

Participants reported being highly satisfied with the content and layout of the talking book, indicating it was comprehensive, logical, and non-technical. One female patient described it as a book that you could 'float' through, meaning it did not require much intellectual effort. Patients wanted information that was clear and easy to understand, particularly at a time when their physical and mental health was diminished due to their diagnosis and treatment (Table 3).

Most participants were very positive about the use of illustrations and photos because it reinforced the written information. Retrospectively, participants spoke about being 'freaked out' by the treatment machines, and how the visual images created a realistic idea of what to expect. There was no consistent preference for either photographs or cartoon illustrations, with some feeling photos were more realistic, whereas others felt the illustrations were less confronting and clinical, and more 'down-to-earth'. Several participants suggested both illustrations and photos be used to complement each other.

When to use the talking book

Retrospectively, most patients and caregivers indicated that the initial appointment with the radiation oncologist was thought an ideal time to provide this resource to patients as it represented a critical time in their treatment trajectory (Table 3). Despite receiving verbal, written, and audio-visual (DVD) information, the nature of the treatment procedure was largely 'unknown' and some described feeling in the 'dark' and unprepared. Many wished they had received the talking book prior to starting treatment so they could have taken it home.

Perceived benefits and challenges of using the talking book with the cancer care team and others

Participants envisaged several challenges and benefits of using the talking book when interacting with members of the cancer care team (Table 4).

Key changes to the talking book based on qualitative analysis

Based on participants' feedback, several modifications were made. We reduced the size of the booklet from A4 to slightly

Table 3 Appraisal of the content, structure and language of the talking book

Sub-theme	Findings	Illustrative quotes
Very satisfied with the content, language and layout	<ul style="list-style-type: none"> • Described talking book as <ul style="list-style-type: none"> - comprehensive - logical - easy to understand - non-technical - well-spaced out 	<p>I thought it was a very good length, it's not deep reading. I think that's what you really need if you are not in good health or feeling happy. (patient no. 29, male, age 61, skin cancer)</p> <p>I like it because when you are not feeling well it's easy to look at. (patient no. 41, female, age 72, skin cancer)</p> <p>The talking book strikes a good balance between a good coverage of the main issues and it does not go too deeply into a whole lot of medical terminology (caregiver no. 4, male, age 58, caring for wife)</p>
Information was perceived as empowering	<ul style="list-style-type: none"> • Help to alleviate concerns prior to treatment commencing • Better understanding of the treatment procedure • Valued glossary in explaining unfamiliar terminology and concepts 	<p>I thought it was well set out, explains a lot, gives definitions of words which people hear every day but really do not grasp (caregiver no. 6, male, age 73, caring for wife)</p> <p>The way it sets out the steps is helpful. I mean at least people will understand what's involved in the planning day, the planning morning or appointment and it takes some of the fear out of it I think. (patient no. 52, female, age 71, gynaecological cancer)</p>
Positive about the use of illustrations and photos	<ul style="list-style-type: none"> • Reinforced the written information and broke up the text • Created a realistic idea of what to expect in preparing for, and having treatment (e.g. the images of a patient having a CT scan and the treatment machine—linear accelerator) • No consensus preference for either photographs or cartoon illustrations—photos were more realistic, illustrations less confronting and more 'down to earth' • Participants suggested using both illustrations and photos to complement each other 	<p>So the pictures I thought were explanatory because there's one picture there of the machines and that was the type of machine I had. Because you have got a photo of it and got an illustration of it, makes it much easier to understand. (patient no. 41, female, age 72, skin cancer)</p> <p>I think the drawings are more light-hearted and it takes away that serious heavy feeling, whereas the photos they give you an idea of what's going to happen naturally. I think you need both, one offsets the other. (caregiver no. 5, female, age 83, caring for husband)</p>
Preferred timing of talking book	<ul style="list-style-type: none"> • Most participants felt it was important to receive the talking book before starting treatment. • The ideal time was the initial appointment with the radiation oncologist. 	<p>Q: When should patients receive the book?</p> <p>A: Once it's confirmed that they will need radiotherapy and after the doctor has had an initial conversation (patient no. 14, female, age 34, brain cancer)</p> <p>I think the appropriate time would be to give this to someone once it's recommended that this is the type of treatment. You can ask questions, but what you really need to do is to go home and think about what's been said, and this booklet at that time would be very helpful to start understanding what is planned. (patient no. 29, male, age 61, skin cancer)</p>

larger than A5 based on feedback that it could not fit well in participants' bags. In response to the confusion around the term 'talking book', we renamed the resource, 'Understanding your radiation therapy treatment: a guide for patients and families'. In the introductory pages, we explained there is an audio version of the book and includes a headphone icon on each page to raise awareness about the audio feature. The front cover illustration is of a person reading and listening to the book.

We integrated a flowchart to illustrate the different treatment pathway time points and used illustrations to represent each time point. To improve readability, each section was colour coded and tabs were included to more clearly delineate between sections. Several changes were also made to some of the terms (e.g. treatment couch replaced with treatment bed). We added information to clarify that these lasers (to position patients correctly during treatment) are not harmful and have no effect on the body, and that the equipment (e.g. masks) and

treatment machines may look different depending on the hospital delivering treatment.

The final version of the talking book can be found at: <http://www.psychosocialresearchgroupunsw.org/other-resources.html>

Discussion

We successfully developed a comprehensive radiation therapy talking book for patients and caregivers prior to starting treatment. Feedback indicated a high level of acceptability for this resource, describing it as useful, relevant, clear, and informative. Participants' positive responses suggest it could be an effective resource for preparing patients and their families for treatment.

The talking book was developed iteratively with multiple perspectives (oncology health care professionals, cancer

Table 4 Perceived benefits and challenges to using the talking book with the cancer care team (CCT) and others

Perceived benefits		Illustrative quotes
Facilitate communication with cancer care team	<ul style="list-style-type: none"> • Prompt question-asking • Express concerns 	But it would definitely be a springboard for any other questions that I felt like I needed if at all. (patient no. 14, female, age 34, brain cancer)
Save time during appointments	<ul style="list-style-type: none"> • Save time during appointments as patient can identify relevant questions • Plan questions and issues to discuss with CCT in advance at different times during their treatment • Patient/caregiver can refer to specific sections that are of concern or require further discussion or clarification 	If people did have that booklet when she is explaining anything, because they keep stressing any questions, which is wonderful, but if they had a booklet there in front of them they could go to page whatever and say what does this mean? I do not understand it. (patient no. 56, female, age 72, breast cancer)
Role of the CCT	<ul style="list-style-type: none"> • Help patients/caregivers have a better understanding of the CCT and the different roles that members of the team play in the team 	I had to think again now what role was that person going to play and what did they do and what was that relationship, and just having this sort of list in the booklet of those different healthcare professionals puts it all into context. (caregiver no. 9, female, age 58, caring for husband)
Facilitate communication with caregivers	<ul style="list-style-type: none"> • Support communication with caregivers—enhances understanding of what to expect and understanding medical terminology 	It would educate the family as to what's necessary and what's expected. So I think it's a valid document for the family to read. I think the wording is quite good for both patient and family. As it says it is a guide. (patient no. 29, male, age 61, skin cancer)
Reinforces verbal information from CCT	<ul style="list-style-type: none"> • Reinforces verbal information received from the CCT • Helps prepare patients for what happens before, during and after treatment (e.g. treatment-related side effects, follow-up care) 	I was having the last lot of radiotherapy I had eleven areas but the most painful area were my ankles and I think I got more radiotherapy on the left outside ankle and it has been very sore, very ugly looking but now it's clearing up and my feet have been very puffy, but the book explains that that will happen. So, I knew it would because of my first treatment but it helped me accept it and get along with life a bit better by reading the book and saying that's me at the moment. (patient no. 41, female, age 72, skin cancer)
Empowerment	<ul style="list-style-type: none"> • Using correct terminology • Equipping patients and caregivers with relevant knowledge and language to communicate with the CCT 	I think it gives people a good basis for understanding and if they have more questions then they are more in a position to ask those questions. It would allow them to use the right terminology (patient no. 29, male, age 61, skin cancer)
Perceived challenges		
Organisational culture	<ul style="list-style-type: none"> • Concerns about CCT having insufficient time and already having a heavy workflow. • Some patients perceived that members of the CCT have a standard spiel when communicating to patients, and the inclusion of the talking book during appointments could interrupt the flow of their spiel 	They are busy doing what they have got to do, they explain everything to you when you first go in there, they sit down and explain, go through everything. (patient no. 6, female, age 72, bowel cancer)
Patient factors	<ul style="list-style-type: none"> • Talking book format too large to bring to consultation • Patients reported they have their own way of recording information (e.g. notebook to ask questions, diary) 	The booklet is very large for a treatment appointment. I think that the booklet is like homework for the patient. (Caregiver no. 1, male, age 50, caring for father) I'd not bring the booklet to radiotherapy session. Can write questions on a piece of paper and bring to the session (patient no. 8, female, age 50, breast cancer)
Not wanting to overburden caregivers	<ul style="list-style-type: none"> • Patients expressed concern that caregivers had enough to cope with and did not want to overload them with more information 	I think it's been rather an emotional journey for them watching me go through this and I am sort of at the end of the radiotherapy after the chemo and it's sort of like, I think, they just want to have a little stand back from everything at the moment. So I did not push that. (patient no. 54, female, age 57, breast cancer)

consumers, communication experts, patients, caregivers) and different learning principles (health literacy, adult education, linguistics) contributing to the development and design process. The iterative approach enabled us to create an innovative

intervention, and to identify components of the intervention that were well received, or could be improved and further refined. Although there were few differences between patients and caregivers in their views toward the talking book,

including caregivers in the development of targeted patient and family resources is important in capturing the nuanced and different views of both groups.

The term ‘talking book’ seemed unfamiliar to some, and there were concerns that older patients may not have access to technology to listen to the audio component. However, some caregivers viewed it as their role to help patients access new technology and understand information, a finding previously reported [31]. The suggestion to rename the talking book to ‘audio guide’ was thought to enhance understanding about the nature of the resource. Our findings lend support to the idea that patients and their families would benefit most from receiving the talking book prior to treatment, preferably at the first appointment with the radiation oncologist, enabling them to learn what to expect at the planning sessions [2, 5, 17].

Participants highlighted various benefits and challenges to using the talking book with the cancer care team. Most participants felt the talking book could facilitate communication by prompting question-asking and helping patients plan discussion points in advance. The information seemed to give participants a sense of equality and empowerment in which they acquired knowledge to be able to confidently communicate to the cancer care team using similar language and concepts [32].

Some participants, however, expressed concerns that members of the cancer care team have a standard *spiel* when communicating with patients, and the inclusion of the talking book could interrupt the flow of their information provision. Healthcare professionals have been shown to be resistant in using similar resources in routine practice due to concerns they would impact on the established workflow and increase appointment time [33]. Some participants appeared reluctant to share information with caregivers because of concerns it would overburden them. While caregivers report feeling overwhelmed with providing care, the provision of clear and easy-to-understand information is generally welcomed as it reduces feelings of stress and uncertainty and increases confidence in supporting patients [34].

This study has several limitations to note. Nearly half of the sample were being treated for breast cancer and most were older women who spoke English as a first language. The influence of gender, diagnosis, and age on the findings should be considered in how participants made sense of the talking book. In addition, the study did not include participants who were privately treated or those from rural or remote areas. We had considerable difficulties recruiting patients with low health literacy. It could be that the screening questions were not sensitive enough in detecting low functional health literacy [35, 36], or low health literacy populations were less likely to participate [37]. We also note six participants had higher education, but reported low functional health literacy. This lends support to the idea that low education and low health literacy should not be treated as synonymous, and people with higher education may have difficulties with unfamiliar concepts and difficult terminology [38, 39].

Conclusion

The low literacy talking book resource was well accepted by patients and their caregivers. It was perceived by participants as an innovative way to prepare patients for treatment, but required some modifications to increase understanding of how to use the resource, as well as improving clarity of content. Further research in a larger sample is warranted to examine the effect of the resource on patient knowledge, anxiety, concerns, and communication with the cancer care team.

Practice implications

While this study developed a print-based talking book, this approach lends itself to transfer into an Internet-based resource. With rates of Internet usage reaching over 85% in the Australian population [40], web-based information and decision aids are becoming more readily incorporated into clinical practice [41, 42]. Doing so will allow information to be tailored to the individual patient. It will also generate a more economical and sustainable resource that is broadly accessible, and will ensure that it can be easily and rapidly updated as new information and evidence becomes available.

Although the majority of participants in the current study spoke English as a first language at home, talking book resources may benefit patients from culturally and linguistically diverse (CALD) populations, and address their unmet information and communication needs.

[21]. People from CALD populations are at increased risk of low health literacy, and those diagnosed with cancer experience poorer disease and quality of life outcomes, including higher rates of reported side effects and lower survival rates [43]. Many do not receive written information materials in their own language, and there is evidence that interpreters do not always accurately translate the information provided by oncologists when discussing diagnosis, prognosis, and treatment options with patients [44, 45]. If translated into different languages, the talking book could provide CALD populations with a resource that is accessible in their own language and help to address the communication challenges faced by health care professionals and concerns they might have about the messages received by patients.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

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