

# Movie making as a cognitive distraction for paediatric patients receiving radiotherapy treatment: qualitative interview study

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## ABSTRACT

**Objectives:** To establish the outcomes achieved by using an innovative movie-making programme designed to reduce fear of radiotherapy among paediatric patients.

**Design:** Qualitative descriptive evaluation based on semistructured, qualitative interviews with purposeful sampling and thematic analysis.

**Setting:** Tertiary Cancer Centre.

**Participants:** 20 parents of paediatric patients who had produced a movie of their radiation therapy experience and were in a follow-up phase of cancer management.

**Results:** Participants attributed a broad range of outcomes to the movie-making program. These included that the programme had helped reduce anxiety and distress exhibited by paediatric patients and contributed to a willingness to receive treatment. Other outcomes were that the completed movies had been used in school reintegration and for maintaining social connections.

**Conclusions:** Allowing children to create a video of their experience of radiotherapy provided a range of benefits to paediatric patients that varied according to their needs. For some patients, movie-making offered a valuable medium for overcoming fear of the unknown as well as increasing understanding of treatment processes. For others, the development of a personalised video offered an important cognitive/attentional distraction through engaging with an age-appropriate activity. Together these outcomes helped children maintain self-control and a positive outlook.

## INTRODUCTION

Radiation therapy (RT) is an integral modality in the treatment of cancer in children, either as a primary therapy or in combination with surgery and/or chemotherapy. The actual administration of high-energy radiation beams is painless, but the nature of the treatment process presents a unique set of challenges in terms of paediatric patient compliance.<sup>1</sup> In 2008, radiation therapists at

## ARTICLE SUMMARY

### Article focus

- Independent analysis of a programme where children with cancer make a movie about their radiation therapy experience.
- Qualitative description of semistructured interviews with parents of programme participants.

### Key messages

- A range of benefits were attributed to making a movie including reductions in the child's anxiety and increased willingness to receive treatment.
- Further benefits were attributed to sharing the movie including maintaining social engagement and aiding school reintegration.
- The family and others in the child's social network also benefited.

### Strengths and limitations of this study

- Independent analysis by a team experienced in healthcare evaluation.
- Open-ended questions yielded rich information.
- Only the perspectives of parents were analysed, not those of the children themselves.
- Only parents of children with favourable treatment outcomes were interviewed.

the Peter MacCallum Cancer Centre in Melbourne, Australia introduced a Movie-Making Program (MMP) to help alleviate the distress that young patients frequently experience during the 7 weeks that treatment typically occurs.<sup>1</sup> As part of this intervention, participating children produce a short creative video describing each patient's journey in their own words. In this article we present findings from an independent evaluation that was undertaken to examine the outcomes of this novel psychosocial intervention.

<sup>1</sup>Treatments are usually daily, last between 15 and 45 min and are delivered in an outpatient setting.

## Background

Radiation does not discriminate between malignant and healthy tissues and therefore must be targeted precisely to ensure tumour kill while minimising dose to surrounding tissues. Precise delivery is of particular importance in paediatrics due to the smaller size of the patient, the impact of radiation on the developing body and because survivors of childhood cancer may live with the side effects of treatment for decades. Owing to this, radiotherapy often requires the use of immobilisation devices to support the patient in maintaining a predefined position. Some of these, such as thermoplastic masks used during the treatment of brain tumours, can be highly confronting to young patients. The treatment machines themselves are also large and imposing and the radiation they create is an order of magnitude greater than that of diagnostic x-ray equipment. This precludes parents from staying with the child during the treatment exposure, often resulting in separation anxiety.<sup>2 3</sup> It is therefore common for young children to require general anaesthetic or sedation on a daily basis for their treatment.<sup>4</sup> Perhaps, not surprisingly, paediatric patients frequently exhibit a strong (and for some almost phobic) dislike of radiotherapy which can result in anticipatory anxiety and treatment resistance.<sup>3 5-7</sup> This can be compounded by treatment side effects such as fatigue and hair loss, as well as the difficulty patients experience when trying to explain radiotherapy and its effects to peers and family.

Over the past 25 years, a growing body of literature has emerged identifying non-pharmacological practices that contribute to reducing the anxiety and distress experienced by children who receive radiotherapy, and in paediatric oncology more generally.<sup>8</sup> For example, studies have indicated that familiarising patients with equipment, staff and treatment processes helps to decrease fear of the unknown.<sup>5</sup> Using distraction to shift the child's attention off stressful procedures is also widely accepted as an effective intervention for promoting comfort and reducing anxiety.<sup>9</sup> Meanwhile, providing activities that offer choices and opportunities for decision-making have been shown to assist paediatric patients in maintaining or regaining a sense of control and mastery in hospital settings.<sup>10 11</sup> Furthermore, evidence suggests that patients who receive support from classmates and friends have lower levels of anxiety and are less likely to experience depression than those who do not receive such support.<sup>12 13</sup> Finally, acknowledging the central role family plays in the well-being of children, paediatric care settings are increasingly implementing practices that facilitate family involvement in treatment processes.<sup>11 14</sup>

## The 'Movie-Making Program'

The primary aim of the MMP is to engage paediatric patients in an enjoyable and distracting activity which will also assist the child to better understand radiotherapy and to explain their treatment experience to those

around them. With this in mind, movies explore treatment procedures in an age-appropriate style and are highly personalised to include the child's interests. For instance, as we illustrate in the compilation video accompanying this article, movies can interweave descriptions of facial masks and equipment with storytelling, puppet shows or favourite hobbies such as motorbikes and football. Consultation with the child and their family is therefore a key component of the production process. Radiation therapists who have an appropriate understanding of radiation safety procedures and privacy requirements create the movies. However, patients are involved both in filming and in postproduction activities, enabling a continuing engagement until the final production is complete and they receive a copy of their movie.

## METHODS

### Evaluation design

To explore the efficacy of the MMP a developmental evaluation was undertaken using qualitative interviews with parents of paediatric patients who had participated in the programme.<sup>15</sup> Consistent with this evaluative approach, the principal aims of the study were to (1) inform ongoing programme development, as well as to (2) provide feedback to staff, and accountability to hospital management through documenting outcomes produced by the MMP. To obtain an impartial view of the programme, the study was conducted by an independent academic centre with expertise in health programme evaluation.

### Study participants

A non-probabilistic 'criterion-based' sampling strategy was used for the evaluation whereby all parents whose children had (1) participated in the programme and (2) who were in a follow-up stage of cancer treatment, were invited to take part in the study (n=40).<sup>16</sup> Parents rather than patients were selected for the evaluation as it was thought that the latter group were well positioned to consider outcomes of the MMP in relation to their child, and others including family and the child's peers. Parents were also chosen as we were keen to avoid the possibility of causing recovering paediatric patients anxiety or distress. Prospective participants were contacted via mail with 20 parents agreeing to join the evaluation (50% response rate). [Table 1](#) provides the age, gender and diagnoses of the respondents' children who had completed the MMP. The period in follow-up at the time of interview ranged from 4 to 37 months (average 10.8 months).

### Interviews and analysis

Ethics approval was granted by the Peter MacCallum Cancer Centre Human Research Ethics Committee. Data for our evaluative study were collected using qualitative semistructured interviews. Semistructured

**Table 1** Characteristics of interviewee's child that had received radiotherapy

Male	Female
8	12
Age	No
3–5	5
6–9	6
10–12	5
13–15	4
Diagnoses	No
Acute lymphoblastic leukaemia	1
Anaplastic ependymoma	3
Ependymoma	1
Craniopharyngioma	1
Germinoma	4
Glioma	2
Medulloblastoma	3
Hodgkin's disease	1
Nasopharyngeal carcinoma	1
PNET	1
Rhabdomyosarcoma	1
Wilm's tumour	1
Region	No
Brain	12
Brain and spine	4
Face and neck	2
Chest	1
Abdomen	1

PNET, primitive neuroectodermal tumour.

interviews were chosen to ensure that informants responded to the same set of questions while allowing opportunities to explore topics raised by the interviewee. Interviews ranged from 20 to 60 min in duration and asked parents to describe any outcomes (positive or negative) they believed the MMP had generated for their child or others (including the parents themselves). Questions about programme outcomes were deliberately broad as we wanted to capture all forms of programme impact as defined by respondents. Parents were also invited to suggest ways the MMP could be improved.

Sample questions from interview schedule:

- ▶ Why did you decide to get involved in the movie-making programme?
- ▶ How was your child dealing with things emotionally prior to the movie-making programme?
- ▶ In what ways has your child's movie been used?
- ▶ If you felt there were benefits/outcomes from being involved in the program, what were they?

The interview data were analysed using thematic analysis techniques.<sup>17</sup> Following the completion of participant interviews, digital audio recordings were transcribed verbatim. Transcripts were then coded, beginning with a preliminary set of codes based on the interview questions and a review of relevant literature.<sup>9</sup> Codes were maintained, adapted, added to or collapsed following further close reading of the interview texts.

Next, all major ideas were displayed under thematic headings on matrices of the type proposed by Miles and Huberman.<sup>18</sup> These displays, in combination with verbatim quotes from the transcripts, are a particularly rigorous way of dealing with qualitative data.

## RESULTS

Respondents were unequivocal in their praise of the MMP, with all parents attributing a wide range of outcomes to (1) the process of being involved in the MMP, and also to (2) the final product of the MMP—their child's personalised movie. These two categories (process outcomes and product outcomes) are used below to report our major evaluation findings. Quotes that illustrate these two overarching findings categories are provided in boxes 1 and 2.

### Outcomes associated with the process of making a personalised movie

#### Provides attentional distraction

One of the most commonly reported outcomes of the MMP (n=16) was that the programme had been highly effective as a cognitive/attentional distraction. An important aspect of this finding was that the nature and degree of distraction generated by the MMP appeared to vary among different patients according to their needs. For example, for children who did not find radiotherapy stressful, participating in the MMP helped to

### Box 1 Outcomes associated with the process of making a personalised movie

#### Attentional distraction

"It was a great diversion ... something enjoyable to look forward to when they're doing something that's not particularly fun. It was exciting for her to be sourcing props, talking about each next step (of the movie) ... and all the time not be scared by the treatment, it took her mind off it completely."

#### Ease with the treatment setting

"That's another part of it (the MMP), the trust factor it creates. She placed a lot of trust in them and she really loved them ... And I think because of that she felt safe. She felt she was not going to be let down and that she could go through the process with the people around her."

#### Cooperation and motivation

"When we were first going in he was all 'I don't want to go and I hate it and it's boring and driving is boring'. (But during the MMP) he would get in the car with a smile on his face rather than crying and refusing to get in because he was happy he was going to make his movie."

#### Other MMP process outcomes

"Our boys didn't take the news to well that Zowie was sick. They got to be part of the movie, which they loved and it was good for them to see what she went through, how the treatment was done and that she wasn't harmed in any way and was safe."

### Box 2 Outcomes associated with the completed personalised movie

**Explaining radiotherapy experiences to school peers and teachers**  
“Lisa was facing some bullying so she showed the DVD to her class to help them comprehend what was going on ... that they could still play with her and there was no need to be calling her names because her hair was falling out. So as far as coping and being accepted at school I think it helped a lot.”

#### Maintaining social connections with friends

“I think he felt better about missing out on the normal stuff, because he was able to tell and show them why. And they didn't make him feel like he missed out on anything, it was more like ‘wow, look what Mark's been doing’. It helped him feel that six weeks out of his life hadn't made him an outcast.”

#### Sharing radiotherapy experiences with extended family and family friends

“Being able to send a copy of the DVD to America for the family to see was just awesome. They understood what was happening and they could see she wasn't afraid. They could see she was coping. So the family fear was not there when they called to talk to us. It was a huge positive spin off.”

#### Other MMP product outcomes

“He still watches it now because it reminds him this is all for something. It helps him to sit down and accept he has to take medication forever ... that it's all for a reason.”

take the patient's mind off the tedium and boredom of repeated visits to the Peter McCallum Cancer Centre for radiotherapy sessions. Meanwhile, the MMP-assisted children who were frightened of radiotherapy to redirect their attention to movie planning and production tasks (eg, discussing storylines, choosing music and filming and editing footage) that were viewed as ‘exciting’ and ‘fun’. For other children, overwhelmed by diagnosis, hospitalisation and cancer treatment processes, the MMP successfully provided a ‘desperately needed’ distraction from the ongoing distress caused by these experiences.

#### Assists patients to be more at ease in the treatment setting

In addition to detailing how the MMP had been an effective distraction, three-quarters of interviewees (n=15) also described how the programme had resulted in their child becoming positively disposed to the RT treatment setting. For instance, parents discussed how the MMP provided opportunities for self-expression, decision-making and also supported patient efforts to explain their treatment experience to others. This, combined with RT staff participating in patient movies (in production roles and frequently as actors), produced a sense of a more personalised treatment process whereby the child, rather than their illness, was recognised, made to feel special and cared for. Moreover, parents explained that by interacting with hospital personnel in

a non-clinical and often humorous manner the child's trust in RT staff was strengthened significantly, and their fear of radiotherapy processes further reduced.

#### Improves cooperation and motivation

According to 14 interviewees, an important benefit stemming from the previous two outcomes was that the child showed a greater willingness to undergo radiotherapy treatment. Again, this occurred in a variety of ways. For some less-resistant patients, the MMP provided an opportunity to engage in an enjoyable activity and so became ‘the one thing that excited and motivated (the child) to be going in each day’. Meanwhile, several parents of previously resistant patients recalled how the anticipation of doing MMP activities had changed their child from having to be bribed with various inducements to attend RT sessions to subsequently ‘urging’ parents to get into the car pleading ‘We've got to go in! We've got to go in!’ Indeed, one parent reported that their child (aged 7) had cried when told she would not be visiting the radiotherapy unit to work on her movie because it was the weekend.

Furthermore, four of the five respondents in our sample whose children had required general anaesthesia during radiotherapy credited the MMP with assisting their child's transition to sedation or to ending the use of anaesthesia altogether. Two of these parents explained how their daughters had been highly fearful of RT sessions, which they attributed to sedation delirium combined with their child's lack of understanding of what occurred during RT sessions (due to being anaesthetised). Both parents were strongly of the view that (1) watching DVDs produced by past patients, and then (2) viewing a video of their own treatment under light sedation, resulted directly in their child becoming cooperative and compliant with treatment requirements while awake. The vignette in box 3 provides a case example of one of these experiences.

#### Other MMP process outcomes

Finally, 12 respondents indicated that the process benefits of the MMP had extended beyond their child to other family members. Parents described how seeing their child smiling and laughing rather than ‘scared and refusing to get in the car’ had helped to lessen their own emotional distress. Nine members of this respondent group further noted that involving siblings in MMP activities and/or improvements in the cancer patient's well-being had contributed to alleviating the concern and worry expressed by brothers and sisters. Parents also commented on how the MMP served as a welcomed distractor at home for all family members, where conversations about making the child's movie provided ‘something fun to think and talk about ... instead of the other doom and gloom aspects of treatment and (cancer management)’.

**Box 3** A vignette of outcomes attributed to the MMP

Before participating in the MMP Lucy (aged 4) exhibited significant stress and anxiety prior to radiation therapy. Because of this, and her young age, Lucy was anaesthetised to ensure that she was compliant during RT sessions. However, due to emergence delirium she would rouse screaming, which compounded her fear of treatment. In an attempt to reduce her growing distress, for one treatment session Lucy was heavily sedated rather than anaesthetised and this session was filmed. She was subsequently shown a movie of herself calmly receiving RT. In the following quote Lucy's mother describes what she believes were the outcomes from participating in the MMP:

'It was unbelievable ... Lucy's whole manner changed. She had been very withdrawn and difficult to talk to—we had to almost pull her kicking and screaming into the radiation treatment room. (She then became) a little girl who took control of the situation for herself because she saw what she was doing ... so we went from a little girl that we were bribing and carrying to the car, at home my husband had to carry her into the car kicking and screaming and hold her down and put her in the car every day ... a little girl who wouldn't look at me in the face, who became very withdrawn, sad and upset to a little girl, to you won't believe it—she used to skip down to the radiation room when it was her turn and would tell us what she was going to do'.

Lucy's mother explained that because her daughter had seen on the video what radiation treatment involved, and that she was well supported and cared for during treatment, her fear of receiving RT 'vanished'. Instead, Lucy developed an understanding of the need to be still during treatment and no longer required anaesthetic or sedation. Lucy's mother identified the 'light-hearted' tone of the DVD and encouragement by puppet characters that featured in the video as playing an important role in this transformation. Watching the video at home also provided 'more positive reinforcement of how wonderful she was and how brave' and contributed further to her willingness to receive treatment.

**Outcomes associated with the completed personalised movie**

In addition to praising the process benefits of the MMP, parents described at length how the end product of the MMP, the child's completed movie, had played a significant role in (1) school reintegration, (2) maintaining social connections with the child's friends and (3) was used extensively for explaining the child's radiotherapy to extended family and family friends.

**Assists efforts to explain radiotherapy experiences to school peers and teachers**

Regarding school reintegration, 14 interviewees reported that the completed personalised movie had been shown at their child's school or preschool setting to account for class absences as well as treatment side effects such as hair loss and fatigue. Many of these respondents said that using the movie in this way had assisted teachers and peers to understand the patient's treatment experience, which often resulted in a ground swell of support for the child and in four cases, reduced incidents of teasing and bullying. Moreover, parents reported that

showing the movie at school had been a 'boost to (the child's) selfconfidence' as the paediatric patient subsequently felt better understood and more accepted by their classmates. Several interviewees, whose child either moved school or entered a new grade, had also found the movie to be an important aid when explaining to new teachers the child's health state and any delayed educational outcomes.

**Contributes to maintaining social connections with friends**

Just over half the parents we interviewed (n=11) described how the movie had played a significant role in mitigating rifts and/or strengthening ties between their child and the child's friends. Respondents outlined how irregular contact with friendship networks due to RT sessions together with the struggle friends experienced grasping 'what radiotherapy actually is' contributed to their child's sense of isolation and being 'out of the loop'. Parents went on to describe how their son or daughter countered this by using their personalised movie to make RT 'tangible and real' for friends, who were in turn 'quite amazed (and) able to see things from a whole different perspective'. Many of these parents relayed how their child's friends were also taken by the antics and humour of the personalised movies, which provided 'cool things to talk about' and so helped the child to feel they had something new, creative and positive to contribute in their interactions with friends.

**Allows radiotherapy experiences to be shared with extended family and family friends**

Beyond the paediatric patient's peers and friends, participants (n=19) detailed how their son's or daughter's personalised movie had been shown and distributed extensively (by the child and parents) among extended family and family friends. Interviewees indicated that the completed movie had proven invaluable for communicating the child's RT experience to these groups, and particularly to concerned family members living abroad. Elaborating on this point, participants discussed how the informative and lighthearted nature of the movies had left viewers feeling less distressed and more at ease asking questions about the child's health state. Furthermore, interviewees said that the positive portrayal of their son or daughter had allowed friends and family to see the child was 'more than a sick kid' and instead 'a normal person who was being strong in a difficult situation'. This in turn generated expressions of admiration that left parents feeling 'genuinely understood' and the paediatric patient 'brave and special'.

**Other MMP product outcomes**

A final major finding that emerged from our interviews with parents concerned the future use of their child's movie. Eleven respondents were firmly of the view that the movie would be employed by their son/daughter to recall and make sense of what had occurred during radiotherapy, as well as their experience of battling

cancer more generally. Several stated this had already happened, with one parent commenting that he had been relieved to find his son watching the movie 2 years after it had been made ‘...because that’s really healthy, (RT) is not something you should just shut away’.

## DISCUSSION

Several authors have evaluated non-pharmacological methods of improving compliance in children undergoing RT. Klosky *et al*<sup>19</sup> reported a randomised evaluation of the anxiolytic effects of viewing a modelling video with an interactive ‘Barney’ the dinosaur doll. Slifer<sup>20</sup> reported a case series of children who complied with RT requirements without anaesthetic while watching videos. Willis and Barry<sup>21</sup> expanded on this system to include the option of closed circuit TV contact between the child and parent to reduce separation anxiety during treatment delivery. Both these video systems permitted a degree of selection by the patient as to either the content watched and/or the manner in which the system was used. A number of other authors described further personalisation to the individual patient in programmes which aimed to effectively prepare patients and families for the demands of radiation treatment.<sup>5 7 22</sup> Barry *et al*<sup>23</sup> evaluated a music therapy approach whereby children composed simple pieces of music which were then remixed to create a personalised CD that they listened to during initial radiation treatments. The MMP has similarities with these methods, but there are several novel aspects. These include the degree of personalisation in the patient-driven story telling and the use of personalised video production in this manner. These aspects appear to be novel, not just in this context, but in health more generally. It also differs from the other methods in its intended aim of helping children explain their treatment to others, rather than purely focussing on the patient’s anxiety and compliance.

Reductions in anxiety and improvements in compliance were reported by parents participating in the study, along with a wide range of other outcomes they enthusiastically attributed to the MMP.

### A smorgasbord strategy

An apparent strength of the MMP is that it provides what Jay and Turk have, respectively, described as ‘package’ or ‘smorgasbord’ strategy that incorporates all the previous mentioned practices, thereby allowing paediatric patients to benefit from the programme in different ways.<sup>24 25</sup> A brief case example helps to demonstrate how this seemed to occur for patients associated with our study. Pippa, a ‘scared’ and ‘distracted’ preschooler, was shown MMP videos produced by patients of a similar age. Seeing other children singing, dancing and laughing as part of their radiotherapy-modelled positive coping behaviours and increased the patient’s familiarity with RT procedures. As a consequence of

viewing others receiving treatment, combined with the motivation to have fun creating her own movie, Pippa subsequently exhibited little fear of radiotherapy to the extent that (like the patient in box 3) she no longer required anaesthesia. Pippa then went on to produce a video in the style of a fairytale, in which her radiotherapy treatment facemask took on magical qualities that only Pippa could control. Pippa’s mother noted how the production of the video provided a much-anticipated distraction from the seriousness and discomfort of daily radiotherapy, and was a vehicle for Pippa to express self-confidence and control in a frightening and life-threatening situation. Beyond these outcomes, Pippa’s mother also recalled how being able to involve her daughter’s twin sister in the movie’s production (an activity that allowed the two children to play and laugh together) gave the family a sense of normalcy and close involvement in Pippa’s treatment.

This example was far from unique in our evaluative study, with almost all interviewees speaking of the ‘empowering’ and ‘self-reinforcing’ benefits of the programme and how this contributed to their child’s adjustment, coping and compliance with RT.

From a clinical standpoint, a programme that was intended to be an enjoyable distraction has yielded substantive outcomes for the patients. The benefits to the clinical department were not dealt with directly in these interviews, but can be inferred from aspects such as reduced anxiety and avoidance of general anaesthesia. The emotional well-being of a patient’s social network is not a typical focus for healthcare providers, but consideration appears to be warranted in paediatrics given the potential impact on patient compliance.

### Improvements to the MMP

Like many psychosocial interventions, the MMP has a low resource base and to a large extent relies on the time donated by clinical staff. While our respondents admired this, five participants pointed out that it also impacted on programme delivery. For example, several said they had not been approached to take part in the MMP until their child was well into their RT treatment, and would have appreciated the ability to begin the programme earlier. Another described how the length of time their child participated in the programme was too short, and that the benefits of the programme would have been maximised if participation had been longer. Two parents also mentioned there had been a month delay before they received the completed personalised movie, and felt that obtaining the final movie during the last stages of treatment would have enabled the child to share their experiences with school friends.

Although these comments were not widespread, they nevertheless highlight the very obvious role of funding in effective programme delivery.<sup>26</sup> With the MMP, the root cause of the issues identified by our interviewees was the lack of time that staff could provide to the

programme. Indeed, while novel programmes like the MMP can be valued by hospital administration for their contribution to supportive care, patient satisfaction with services and even for generating positive publicity, without appropriate funding they run the risk of becoming ad hoc activities, or, to end abruptly when key staff move on. A key challenge then for the MMP, and similar innovative psychosocial programmes, is to establish a secure funding base as without it sustainability is questionable, and the benefits to patients' risk being lost.

### Study strengths and limitations

The strengths of this study reflect those of qualitative research in general. These include that rather than responding to preconceived outcome categories, participants outlined what they perceived to be the benefits of the programme freely. Using open-ended questions also enabled us to generate extremely rich, detailed and unexpected information regarding participant views and experiences of the MMP. Additionally, the ability to use prompts and probes during interviews provided opportunities to explore the how and why of participant responses.<sup>27</sup> Finally, the impartiality of the results was enhanced through the study being undertaken by an independent evaluation centre with no institutional affiliation with the radiation treatment unit.

At the same time, the study clearly has a number of limitations. The first of these is that we have relied on the perspectives of parents and have not also included paediatric patients. This decision was made in part due to the young age of some programme participants, but principally to avoid the possibility of causing an extremely vulnerable group further distress. Furthermore, we recruited study participants whose children had favourable outcomes following cancer treatment. This was a deliberate choice so as not to contribute to the anguish or sorrow of parents whose child was critically unwell or no longer alive. We acknowledge the latter parent group may have provided a different view of the programme. The perspectives of this group and the perspectives of the children themselves are challenging, but fascinating areas for further research.

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